University of Alberta

# Women Caregivers of Older Adults with Cognitive Impairment: Perceptions of Formal Support

by

Myrna Heinrich

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the degree of Master of Nursing

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The undersigned certify that they have read, and recommend to the Faculty of Graduate Studies and Research for acceptance, a thesis entitled **Women Caregivers of Cognitively Impaired Older Adults: Perceptions of Formal Support** submitted by **Myrna Heinrich** in partial fulfillment of the requirements for the degree of Master of Nursing.

Dr. Anne Neufeld, Supervisor

Dr. Margaret Harrison

Dr. Margaret Haughey

Date: April 9, 1998

## Dedication

This book is respectfully dedicated to the caregivers

who gave generously of their time in order

to share their caregiving experiences

so that others may learn from them.

Abstract

The purpose of this study was to explore perceptions of formal support of women caregivers of older family members with cognitive impairment. The study involved secondary analysis of data from interviews with 20 caregivers, followed by focus group discussions involving participants recruited from the original study. A core and supporting theme portraying their perceptions of formal support and factors influencing their perceptions were identified using grounded theory techniques for data analysis. The core theme, "Keeping the Vigil" involved continuously checking the status of the care recipient and searching for information useful in dealing with caregiving issues. Preservative caregiving, the supporting theme, included both personal care of the relative and strategies to access formal support. Caregiving actions and interactions with formal providers were influenced by the womens' perceptions of themselves and the care recipient. The findings add to our understanding of caregivers' experience with formal providers and suggest new areas for research.

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# Chapter 1

## Introduction

Families continue to be the primary source of assistance to older family members with cognitive impairment. Women, particularly wives and daughters, are the most frequent major caregivers (Chappell, 1992). Increased recognition of the contributions made by family caregivers has resulted in greater awareness of demographic trends which may limit their ability to provide care on their own in the future (Horowitz, 1985).

Considerable interest has been generated in examining the impact of caregiving on the health of the informal caregiver. Social support research has established that women who are caregivers of cognitively impaired elders frequently report symptoms of depleted physical and/or mental health. Further to this, relationships between social support and a variety of physical and mental health outcomes in caregivers have been explored (George & Gwyther, 1986, Gilhooly, 1984). Positive effects of social support have been reported; however a lack of consensus in the conceptualization and operationalization of the concept of social support has led to inconsistent findings, thus impeding our understanding of the factors within social relationships which influence health.

There is evidence that the well-being of women who are caregivers of older adults who are cognitively impaired is not necessarily related to the severity of the care recipient's dementia or the length of the illness. Instead, a more consistent relationship has been found between caregiver well-being and the perception that help

is available from one's support network if it is needed (George & Gwyther, 1986). Although research studies have attempted to measure perceived support, the processes and interactions through which perceptions of support influence health require further study. Perceived support is a significant concept for nurses and other health professionals who are in frequent contact with dementia victims and their caregivers in a variety of settings.

## Statement of the Problem and Purpose

Despite an abundance of research in the area of social support, adequate theoretical descriptions of the mechanisms through which perceived support influences health are lacking. It is timely to explore the perceptions of formal support held by women caregivers of cognitively impaired elders. The knowledge gained from this study will address a present gap within the social support literature by contributing to the development of descriptions of the processes through which social support operates, and will have implications for planning appropriate, health promotive interventions in the future. The purpose of this study is to explore the perceptions of formal support held by women as they care for an older adult family member with cognitive impairment.

## Research Question

The central research question that guided this study is:

*What perceptions of formal support do women caregivers experience as they care for an older adult family member who is cognitively impaired?*

Additional guiding questions included:

"How do women caregivers describe the formal support they receive as they care for their family member?"

"Do the women caregivers' perceptions of formal support change over time as they care for their family member?"

What are the differences in perceptions of formal support described by the women caregivers?"

## Definition of Terms

**Social support** - Social support refers to interactions with individuals within one's social network which communicate information, esteem, aid and reliable alliance. These communications improve coping, moderate the impact of stressors, and promote health (Stewart, 1993).

**Social network** - A social network includes all people with whom an individual may have contact or an exchange (Chappell, 1992), and encompasses both formal and informal networks. A social network consists of "...a set of nodes...connected by a set of ties....nodes may be groups or organizations as well as persons, and ties may be dependency relations or flows of resources as well as friendship or kinship ties" (Wellman, 1981, p. 173-178). The contents of ties change over time, vary in strength and symmetry, and involve support and/or nonsupport (Wellman, 1981).

**Informal support** - Informal support is the support rendered by lay people such as family, friends, neighbours, peers, coworkers, community leaders, volunteers and self-help groups within an individual's social network (Stewart, 1993).

**Formal support** - Formal support refers to supportive interventions by health

professionals or others within the health care system (Chappell, 1992).

**Perceived support** - "...refers to a generalized appraisal that individuals develop in the various role domains of their lives in which they believe that they are cared for and valued, that significant others are available to them in times of need, and that they are satisfied with the relationships they have" (Heller, Swindle & Dusenbury, 1986).

# Chapter 2

## Review of the Literature

Family members, particularly women, continue to be the primary source of assistance to older family members with cognitive impairment. Societal and demographic trends indicate that the number of informal family caregivers will continue to increase; however, there is concern regarding the ability of caregivers to manage the demands of caregiving on their own over an extended time period in the future. Provision of formal support to caregivers and their family members is viewed as an important aspect of enabling family members to continue in the caregiving role.

The literature will be reviewed with respect to caregiving for a family member with cognitive impairment, women as caregivers, caregiver well-being, and formal support as a mediating factor in caregiving situations and in caregiver health. Relevant qualitative and quantitative research findings will be discussed.

### Caregiving

A significant and current demographic trend is the steadily increasing proportion of older adults in the Canadian population. It is predicted that by the year 2031, 20% of all Canadians will be aged 65 and over. Further, nearly one-half of this group will be over the age of 75 (Chappell, 1990). Researchers in gerontology have documented that the informal network of family and friends is the primary source of assistance for seniors in contemporary society who require help. This form of social support, frequently referred to as caregiving, consists of assistance provided to individuals who as a result of deteriorating physical and/or mental health, can no

longer function independently in areas where they did previously (Chappell, 1992). The growing body of knowledge regarding family caregiving of older adults continues to confirm that families wish to maintain involvement with their older family members and respond voluntarily to meet their needs.

Informal caregivers of older adults are often female family members, most notably wives and daughters (Stone, Cafferata & Sangl, 1987). The Canadian Study of Health and Aging (1994) reports that most primary caregivers of elderly people who live in community and institutional settings are married and female. Further, 75.4% of seniors who are demented and live in the community have a female caregiver. Spouses, especially women, are most likely to be named as the primary caregiver among married individuals (Chappell, 1990, 1992). When the senior is widowed, the women in the next generation - that is, daughters and daughters-in-law - are the major caregivers (Brody, 1981).

A number of societal trends are of interest when considering the ability of family members to continue in their role as primary caregiver. First, the increase in life expectancy is contributing to a higher incidence of impairments and complex health care needs that lead to dependency among older adults as age advances. Second, with the exception of the post World War II "baby boom", there has been a trend toward having fewer children, thus decreasing the number of potential family caregivers of older adults. Further, the increase in divorce rates and the resulting changes in family composition may also impact the availability of family caregivers to assist older family members in the future. There is also an increase in the number of

women of all ages entering the labour force. Current economic realities are such that many women do not have the choice of relinquishing paid employment for unpaid caregiving of family elders.

Scarce health care resources in recent years have prompted policy makers to examine alternatives for meeting the health care needs of populations in a more cost effective manner. Interestingly, the restructuring of health care delivery systems has again focused attention on the contributions that family caregivers make in assisting older family members to manage their health needs. In view of the potential limitations on family caregiving just described, there is concern that the health of family caregivers may be overlooked, with the result that both the care recipient and caregiver may become dependent on the formal health care system. This concern has generated interest in studying aspects of informal caregiving which may leave caregivers at risk.

Caregivers of Older Adults with Cognitive Impairment

The loss of intellectual function in older adults due to dementing disorders has become a major societal health concern (Chappell, 1992), In Canada, it is estimated that the prevalence of severe dementia ranges from 2.3% (in the 65 to 74 age group) to 11.1% (in the 75 to 84 age group) to 34.5% in those over age 85 (Health and Welfare Canada, 1993). Thus, the increase in life expectancy is adding to the number of people who are at risk of developing dementia. The most common cause of dementia in older adults is Alzheimer's disease, which affects more than 50% of dementia victims (Chappell, 1992). More recent estimates in Canada indicate that

Alzheimer's disease represents 64% of all cases of dementia, while vascular dementia accounts for 19%. Further, women are approximately twice as likely to be affected as men. (Canadian Study of Health and Aging Working Group, 1994). Alzheimer's disease is a progressively degenerative brain condition with no known cause or cure. It manifests itself through a chronic decline in intellect, memory, judgement, concentration, self-care abilities, and personality.The onset of symptoms is insidious, and there is marked variability in the course of the illness (Watson, 1987).

Caregivers of cognitively impaired older adults are usually either the spouse or daughter, who often care for the family member for a decade or more prior to institutionalization or death (Guerriero Austrom & Hendrie, 1992; Watson, 1987). In Alberta, 70% of all persons with Alzheimer's disease live in their own homes, and the majority of their caregivers are women over the age of 70 (Alzheimer Association, 1993). Often the spouse caregiver is physically frail or suffering from chronic disease, which may interfere with or become exacerbated by the caregiving role (Guerriero Austrom & Hendrie, 1992). Thus, the unique concerns associated with providing care for a cognitively impaired elder may be combined with the concerns of female caregivers discussed previously. However, in a qualitative study Opie (1994) cautions that gender-specific notions of women caregivers portrayed in the literature do not take into account the complexity and variation in affective caring positions that occur throughout the process of caregiving, thus raising implications for appropriate policy formation that is sensitive to these variations.

The presence of dementia has been cited as a factor that may impact on the

structure and composition of an elderly care recipient's support network. Birkel and Jones (1989) found that demented individuals received fewer hours of care from outside the household and from formal providers than did individuals who were lucid. It is also documented that informal caregivers of Alzheimer's victims receive less assistance from formal sources than other caregivers (Straw, O'Bryant & Meddaugh, 1991). It is suggested that the social stigma associated with dementia, coupled with the variable presentation of dementia from day to day may contribute to the reluctance of caregivers to seek help from outside the household (Birkel & Jones, 1989).

The Impact of Caregiving on the Informal Caregiver

Over the past decade, an abundance of research studies have examined a variety of potential problems that arise for caregivers of older impaired adults. The term "caregiver burden" has frequently been used to refer to the negative implications of caregiving, such as depleted physical and/or mental health, decreased social/recreational involvement and financial difficulties (Chappell, 1992). Other terms which also refer to negative aspects of caregiving include stress, distress and strain. In a review of literature pertaining to the consequences of stress related to caregiving, Schulz, Visintainer and Williamson (1990) concluded that studies of physical health outcomes based on self-report, utilization of health care resources and immune function suggest that caregivers are more vulnerable to physical illness than non-caregivers. Other findings indicate that the most negative impact of caregiving occurs in one's personal life (McKinlay, Crawford & Tennstedt, 1995). Although the literature is now addressing the problems encountered when caring for the physically

frail, the stress associated with caring for family members with Alzheimer's disease and related dementia disorders has been of particular interest.

It is generally well established that the unique aspects of cognitive impairment in an older adult place special additional demands on the caregiver. Caregivers have described feelings of being tied down, and an interference with social life. Care recipient characteristics which are problematic include repetitive questions, sleep disturbance and wandering, and dangerous or irresponsible behaviours which necessitate round-the-clock surveillance (Robertson & Reisner, 1982). Assistance with activities of daily living may also be more difficult and time consuming if the care recipient is resistant. The care recipient's loss of recognition of the caregiver is also distressful (Brody, 1990).

Despite the profusion of descriptive studies reporting stress-related dysfunction in caregivers of dementia victims, little is known about specific factors that may contribute to negative outcomes (Borden, 1991). In her proposed conceptual framework for studying caregiver burden related to Alzheimer's type dementia, Pallett (1990) suggests that variables within four domains impact caregiver stress and well-being: characteristics of the impaired relative, characteristics of the caregiver, characteristics of the relationship between the caregiver and care recipient, and the caregiver's social support resources.

In general, studies have indicated that objective measures of the care recipient's impairments, such as severity of symptoms and duration of illness are not necessarily related to outcome (Borden, 1991; George & Gwyther, 1986; Haley,

Levine, Brown & Bartolucci, 1987; Jenkins, Parham & Jenkins, 1985). Other potential correlates of caregiver burden have been examined, such as demographic characteristics, the number of social supports available to the caregiver, the caregiver's use of formal services, the length of time that care has been provided, and frequency of visits from family; however, none of these variables have been found to be major predictors of burden (Chappell, 1992). Some research findings have suggested that spouse caregivers experience lower levels of well-being than adult child caregivers (George & Gwyther, 1986). The relationship between the care recipient and caregiver has also been examined, with inconsistent results.

Kramer and Kipnis (1995) reported that women caregivers who are employed are more likely to report conflict between their job and caregiving roles, and to experience higher levels of burden. In a review of research that explores caregiving and employment, Tennstedt and Gonyea (1994) concluded that there is lack of a sufficient basis for determining the prevalence of consequences for caregivers who are employed, and that lack of research in this area poses a risk for inappropriate policy formation and therefore potential negative consequences for caregivers.

When comparing caregiver characteristics according to gender, it has been noted that women tend to report higher levels of distress and lower levels of well-being (Borden, 1991; Fitting, Rabins, Lucas & Eastham, 1986). Caregiving wives tend to experience feelings of depression and burden more than caregiving husbands (Pruchno & Resch, 1989). It has also been suggested that women experience greater vulnerability to undesirable life events because they are more emotionally involved in

the lives of those around them (Kessler & McLeod, 1984). Gender differences have also been noted in the relationships of caregivers with their care recipients. Schuster, Kessler and Aseltine (1990) noted that women have more active relations with their kin, they tend to be more emotionally responsive to negative interactions than men who are caregivers, and tend to benefit more from supportive interactions. Others (Pruchno & Resch, 1989) report that the caregiver role is experienced differently by men and women. These are important considerations, given that the majority of informal caregivers are women.

## Social Support

The concept of social support and its impact on health and well being has been a topic of considerable interest over the past few decades. Social support is a multidimensional construct for which varying definitions have been presented in the literature. Social support is conceptualized as: integration of the individual into a social network, support that the individual has received or reported to receive, and support that the individual perceives to be available if it is needed (Sarason, Sarason & Pierce, 1990). Behaviours or acts that are supportive can be generally classified as emotional, instrumental, informational and appraisal (House, 1981). In their conceptualization of the support process, Cohen and Syme (1985) distinguish between the structural perspective of social support, which examines the interconnections within social networks, and the functional perspective, which assesses whether relationships within an individual's network serve particular functions. For the purpose of this study, social support refers to interactions with individuals within

one's social network which communicate information, esteem, aid and reliable alliance and which improve coping, moderate the impact of stressors, and promote health (Stewart, 1993).

The recognition that social interaction can be health promotive has generated a great deal of research activity in the area of social support. Initially, research that addressed the social relationships of older adults focused on describing the nature, extent and sources of their social networks. For instance, the continuing contact between elders and their families was documented at this time. However, it was found that the existence of social interaction did not necessarily indicate that support had occurred; correlations between social relationships and health were not examined until more recently (Chappell, 1992).

Social Support and Health

Growing evidence of the burden experienced by informal caregivers of older adults with cognitive impairment has stimulated exploration of the relationship between social support and caregiver well-being. Findings suggest that there are various aspects of social interaction which are related to health outcomes in caregivers (George & Gwyther, 1986; Gilhooly, 1984; Morris, Morris and Britton, 1989; Robinson, 1990; Scott, Roberto & Hutton; 1986). Woods, Yates and Primono (1989) suggest that the source of support (kin vs. nonkin) is less important to caregiver health than the nature of the relationship between the provider and recipient of care. Caregiver well-being has also been found to be related more closely to characteristics of the caregiving situation and resources available to the caregiver than the condition

of the care recipient (George & Gwyther, 1986). Family support has been positively associated with caregivers' coping effectiveness (Scott et al., 1986). Other results have suggested that social support reduces caregiver strain or depression (Morris et al., 1989). In contrast, another study found no relationship between social support and caregiver adjustment (Robinson, 1990). Research studies in this area have been characterized by a lack of conceptual clarity and inconsistent operational measures of caregiving, well-being, interactions with the social network, burden, and so on, with the result that findings are often contradictory.

Empirical examination of the relationship between social support and health led to different hypotheses regarding the beneficial effects of social interaction. The direct/main effects viewpoint proposes that there is a direct relationship between social support and well-being; social support directly benefits well-being by meeting basic social needs (Chappell, 1992; Stewart, 1993). The indirect/buffering/mediating hypothesis argues that the beneficial effects of social support are evidenced only during crises or stressful events; social support mediates the effect of stressful experiences on well-being, or quality of life (Chappell, 1992; Stewart, 1993). Comparison of research studies that address the direct and indirect effects, however, reveals inconsistent and contradictory results. The general conclusion has been that both direct and indirect relationships occur between social support and well-being (Chappell, 1992; Heller, Swindle & Dusenbury, 1986).

Social support is of particular interest to nurses and other health professionals because of its impact on health, health behaviour and health services utilization

(Stewart, 1993). Health care providers within the formal health care system are in frequent contact with caregivers of dementia victims in a variety of institutional and community settings.

Perceptions of Support

In the literature addressing social support of informal caregivers of dementia victims, caregivers' perceptions of support from family and friends have been more strongly associated with caregiver well-being than illness characteristics of the care recipient (George & Gwyther, 1986; Scott et al, 1986). Research has indicated that caregivers' appraisals of illness characteristics were more predictive of adaptational outcome than the severity of the dementia (Borden, 1991), and were better predictors of depression (Haley, Levine, Brown & Bartolucci, 1987). It has also been found that caregivers with the greatest burden in terms of stress symptoms, poor health and caregiving demands were more likely to perceive their level of support as inadequate (Clipp & George, 1990). Perception of support has been described as a dimension of support that can in itself promote health (Cobb, 1976), whether or not the perception is accurate (Wethington & Kessler, 1986). It is also suggested that the perception of having support available helps to protect against distress by altering one's appraisal of the situation (Cohen & McKay, 1984). Findings such as these have led to the development of instruments to measure social support as the perception that support was available if needed (Procidano & Heller, 1983; Sarason, Levine, Basham & Sarason, 1983). However, it is argued that measurement approaches do not adequately consider the "...part played by support transactions in response to the event"

(Wethington & Kessler, 1986, p. 79), and that the underlying component of perceived support is not yet known (Heller et al., 1986).

Further, it is increasingly acknowledged in the literature that definitions of social support have frequently emphasized the positive side, while negative aspects have been overlooked (Abel, 1989; Chappell & Guse, 1989; Tilden & Galyen, 1987). "Support which is intended by the provider to be positive may be negative either because the objective outcome of the support provided is negative or the recipient of the support perceives the support negatively" (Antonucci, 1985, p. 29). Reciprocity, or the exchange of resources, has been identified as one aspect of social relationships in which elderly people may have a disadvantage, creating the possibility for perceptions of conflict (Antonucci, 1985; Chappell & Guse, 1989). Because of the demands involved in caring for an elder with dementia, caregivers may also have fewer resources with which to reciprocate in social relationships. Thus, it will be important to address social relationships in future research.

Formal Support

The support provided by formal health care providers is considered by some to be conceptually distinct from social support, or informal help (Norbeck, 1981). Others argue that formal sources of support "...should be considered along with or secondary to the more usual lay sources of help..." (Stewart, 1993, p. 10). It is the latter conceptualization which is adopted for this study.

The formal care system essentially provides care for individuals which the informal support system is unable to provide, for whatever reason. It is estimated that

20% of the care to seniors comes from the formal system; the remainder is from the informal system of family and friends (Chappell & Guse, 1989). Related to formal care of seniors is the issue of providing formal support to caregivers of seniors to enable them to continue in their caregiving role. Available evidence suggests that caregivers"...make very judicious use of such services" (Chappell, 1992, p. 9), and use them in conjunction with support from informal sources (Scott & Roberto, 1985). Studies indicate that use of formal sources of support is limited and viewed as a "last resort", despite caregiver knowledge regarding available community resources (Gonyea & Silverstein, 1991). Thus, formal support to informal caregivers of dementia victims is viewed as important, yet little is known about who seeks assistance from the formal system, and why (Chappell & Guse, 1989).

Kosloski and Montgomery (1994) used Anderson's behavioral model (as cited in Kosloski & Montgomery, 1994) to explore factors associated with service use by family caregivers of dependent elders. They found that it is important to consider not only whether the service is discretionary (e.g. adult day care) or nondiscretionary (e.g. hospitalization), but also who is defining the need for service (i.e. spouse vs. adult-child caregiver). Other studies suggest that other factors are related to the use of formal services, such as lack of knowledge about available services (McCabe, Sand, Yeaworth & Nieveen, 1995), or caregiver perceptions concerning the usefulness and convenience of the service (Kosloski & Montgomery, 1993). Caregiver values such as obligation, reciprocity and the need for control were also identified as important in a qualitative study (King, Collins & Liken, 1995).

The use of home care services by informal caregivers as a means of assistance with aspects of caregiving has been examined. It has been reported that there is an absence of reliance on formal service providers (Stoller & Earl, 1983), that caregiver need or stress is predictive of in-home service use (Noelker & Bass, 1989), and users are in worse health than non-users (Chappell, 1985).

In a review of literature related to nursing home utilization by seniors and their caregivers, Kosloski, Montgomery and Borgatta (1990) concluded that little is known about factors surrounding the process of institutionalization. In general, plans to institutionalize occur more frequently when "...the caregiver perceives more burden and if the caregiver's relationship with the elder is less close" (Chappell, 1992, p. 40). Other positive predictors of institutionalization identified included advanced age, being white, dependency in both activities of daily living and independent activities of daily living, prior admission to a nursing home, living alone, and the presence of cognitive problems. Having a spouse or adult child caregiver of at least three year's duration reduced one's chance of being institutionalized (Pearlman & Crown, 1992). Chenoweth and Spencer (1986) reported that caregivers of family members with dementia initially thought that violent behaviour or incontinence would be the factors driving their decision to institutionalize, but found instead that it was related more to exhaustion from constant surveillance of the family member.

It has also been found that caregiver depression and somatic complaints do not necessarily decrease following placement of the care recipient in a nursing home (Rosenthal & Dawson, 1991; Stephens, Kinney & Ogrocki, 1991). Barber (1993)

reported that negative aspects of caregiving were similar among caregivers of both institutionalized and in-home family members with Alzheimer's disease. According to Pallett (1990), the nature of the stressors may simply change to factors such as transportation issues, the emotionally draining experience of visiting, and transitional issues related to relinquishing caregiving duties to others. Other qualitative studies have reported a tendency of family caregivers to monitor the care provided by formal providers, particularly in the nursing home setting (Bowers, 1988; Duncan & Morgan, 1994).

The relationship between caregivers and formal providers in institutional and community settings has also been explored in qualitative research. Caregivers placed importance on the relationship between staff and the care recipient and between staff and the caregiver (Duncan & Morgan, 1994; Hasselkus, 1988); their perceptions of high quality care depended as much on these relationships as on the provision of technically competent care. Similarly, in a qualitative study Forbes (1996) found that elderly clients' satisfaction with home care was influenced by program characteristics, home care workers' attributes, relationships with the workers, and clients' involvement in planning their care. Formal providers' acknowledgement of the prior knowledge held by the caregiver and involving the family in care decisions were important aspects that contributed to a satisfactory relationship between family and formal providers (Bowers, 1988; Duncan & Morgan, 1994; Rutman, 1996).

Bowers (1988) qualitative study regarding care provision in nursing home settings uncovered the priority of many caregivers to provide both preservative

(emotional/ psychosocial) and technical care for the family member; which were considered essential components of quality care. Technical expertise in the absence of preservative care was viewed by the caregivers as inadequate. Provision of both types of care required collaboration with formal providers.

Issues in nursing homes that presented barriers to achieving satisfying relationships with formal providers involved in the care of the care recipient have also been identified in qualitative studies (Duncan & Morgan, 1994; Hasselkus, 1989). Rigid scheduling which guided care provision in the institutional setting (Bowers, 1988) and staff turnover were viewed as a barriers to the provision of emotional support to the care recipient and caregiver (Duncan & Morgan, 1994).

Since physicians continue to be a frequent entry point into the formal health care system, their interactions with caregivers and care recipients have been explored. Findings have revealed that caregivers would like physicians to support and acknowledge their role, and to make referrals to appropriate sources of support as necessary (Glasser, Rubin & Dickover, 1989).

The role of family caregivers as decision makers is also reported in the literature, including the need for formal providers to support caregivers in their decision-making role. Seltzer, Ivry and Litchfield (1987) reported the performance of case management functions by family caregivers of older adults, and discussed the subsequent need for formal providers to view caregivers as partners in care provision. Caregivers have also expressed disappointment with the lack of information provided to them by formal providers which would assist them in their decision-making (Bear,

1993). Although it has been found that family caregivers wish to maintain control over decision-making, physicians are frequently involved in the family decision-making process (Bear, 1993; Deimling, Smerglia & Barresi, 1990).

Other research (Chenoweth & Spencer, 1986) reports the difficulties encountered by caregivers when consulting with their physician regarding a diagnosis, such as articulating the subtle changes that were occurring in the family member in order to convince the physician that something was wrong, as well as struggling with the family member who was often resistive to a medical consultation. Caregivers have also reported that even when a diagnosis such as Alzheimer's disease was obtained, it was not accompanied by information on how to care for the family member. Physicians tended to focus on the hopeless nature of the dementia, and even advised caregivers not to bring the family member back to them, since nothing could be done to help them. In a review of literature pertaining to informal family caregiving of older people with dementia, Adams (1996) noted that family caregivers of dementia victims often care for their relative alone for a period of time before seeking formal help, and that it would be worthwhile to examine the effectiveness of interventions made earlier in the caregiving experience.

Support groups, including self-help groups and professionally sponsored support and information groups (Goodman, 1991), have emerged as a form of social support to caregivers, most notably caregivers of dementia victims (Chappell, 1992). Caregivers have identified positive aspects of support groups such as universality, group cohesiveness and imparting of knowledge, but have also experienced negative

features such as content of meetings, logistics and emotions/feelings (Wright, Lund, Pett & Casserta, 1987). In a study that explored the relationship between Alzheimer caregiver well-being and support group participation, decreased levels of objective and subjective burden were noted. However, caregiver well-being was more closely related to family and care recipient characteristics (Gonyea, 1991). Other studies have had conflicting results, and call into question the validity of constructs used to measure the effects of support group participation (Demers, 1996). The effectiveness of individual and group interventions have also been compared (Toseland, Rossiter, Peak & Smith, 1990). Gonyea and Silverstein (1991) reported an association between support group participation and utilization of formal services; however, further research is needed to examine the linkages. Overall, the studies in this area indicate the need to know more about why and for whom support groups are effective.

The utilization of respite services has also been examined for its potential benefits to caregivers of elders with cognitive impairment. Generally, the use of respite programs has been low. This has led to speculation that cost, feelings of guilt, lack of familiarity with such programs and the potential for deterioration of the elder in the respite facility have resulted in reluctance to use respite services other than as a last resort (Chappell, 1992).

## Related Qualitative Studies

Qualitative research in the area of caregiving for older impaired adults has examined the caregiving experience from the perspective of the informal caregiver, and the meanings caregivers attribute to their experiences. Bowers' (1988) study has

contributed to our understanding of how caregivers view their caregiving role; caregivers provided direct care to preserve the family member's "self", and also monitored and evaluated the care provided by nursing home staff. Other caregivers (Duncan & Morgan, 1994) emphasized the importance of maintaining an ongoing relationship with formal providers involved in the care of their cognitively impaired family member. Technically competent care in the absence of emotional care of the care recipient and caregiver did not meet the caregiver's criteria for quality care. Hasselkus (1988) found that tension occurred in the relationship between caregivers and formal providers whose meanings of the caregiving situations were dissimilar. Other qualitative research has revealed the need for formal providers to increase their awareness of the relationship between the caregiver and care recipient (Chesla, Martinson & Muwaswes, 1994). The provision of timely information to support the caregiver in the process of caregiving has also been identified (Wilson, 1989). These qualitative studies have contributed to our in-depth understanding of the caregiving experience from the perspective of informal caregivers, but have not specifically addressed women caregivers' perceptions of formal support.

## Conclusion

After more than two decades of social support research, a basic understanding of how social relationships are health protective remains elusive (Heller et al., 1986). The absence of theoretically driven research (Barer & Johnson, 1989; Heller et al., 1986) and inconsistent conceptualization and operationalization of the concept of social support (Thoits, 1982) have impeded progress toward its refinement. The

tendency to utilize cross sectional research designs and small volunteer samples are a limitation of many research studies in this area. It is generally accepted that social support is multifaceted, and that not all social relationships are health promoting. Indeed, social support may in itself be an etiological factor (Thoits, 1982) if social ties are a source of stress and conflict, or if support provided is perceived as unhelpful (Stewart, 1993). It is apparent that improved theoretical descriptions of the basic mechanisms through which social support operates are needed if we are to understand the factors responsible for health maintenance and promotion.

As the focus of the health care delivery system moves from a cure orientation to that of health promotion and primary health care, nurses and other health professionals are becoming facilitators, educators and collaborators with health care consumers who are more actively involved in their own care. Social support reflects a lay helping philosophy and is therefore compatible with this premise (Stewart, 1993). It is timely to address factors associated with use of the formal care system by informal caregivers. The present study will begin to address this need.

# Chapter 3

## Method

Caregivers' perceptions of formal support were explored through use of secondary analysis of interview data obtained in a previous study and two focus group interviews with participants recruited from the original study. The previous study addressed perceptions of social relationships and social support held by women caregivers of cognitively impaired older adults, and focused on women caregiver's perceptions of reciprocity within their informal networks (Neufeld & Harrison, 1993). The caregiver's perceptions of formal support were not addressed in the original analysis. In the current study a core and supporting theme of perceptions of formal support, factors influencing perceptions, and perceptions of satisfaction with support were identified using grounded theory techniques for data analysis.

### Data Collection

In the original study, the informants (N=20) were recruited through letters to community agencies and advertisements in local newspapers. All informants spoke English, resided in the Edmonton area, and were caring for a cognitively impaired family member who was 60 years of age or older. Care recipients either lived with the caregiver or in a longterm care institution.

The data for the original study were collected through a series of three to four guided interactive interviews with each informant, conducted over a twelve month period. A total of 62 interviews were completed. Each interview, which lasted approximately 1 1/2 hours was audiotaped and transcribed verbatim. Refer to

Appendix A for examples of the guiding questions used, as well as probes that were developed for subsequent interviews, based on the analysis of each interview. In addition to the interview data, a genogram and ecomap were constructed for each informant, and a demographic questionnaire completed. In the present study, the investigator received access to the audiotapes, transcripts, genograms, ecomaps and demographic data from the original study, as well as minutes of the research team meetings held during the original study.

The data from the original study were appropriate for use in the present study. The purpose of the present study fit well with the purpose of the original study, which addressed the social relationships and supports of women who were caring for a cognitively impaired older family member. Perceived formal support is one dimension of the caregivers' support network which was not addressed in the original analysis. The longitudinal data was also appropriate for exploring the process of caring for cognitively impaired care recipients, and capturing the variability that occurs in individual caregiving situations. The availability of the principal investigator of the original study to provide contextual information regarding data collection enhanced the feasibility of using the data for secondary analysis.

Although each of the women caregivers were at different points in their caregiving experience when the interviews began, they were encouraged to reflect back to the time that they first began caregiving through the question: "Tell me how you came to be a caregiver for your...". Thus, the process of caregiving for a cognitively impaired elder, which often began when the caregiver first noticed

changes in the care recipient and suspected that something may be wrong, and for three of the caregivers, ended in the period following the death of the care recipient, was captured.

In the current study, informants of the original study were invited to participate in a focus group discussion. The purpose of the focus group was to present preliminary findings arising from the secondary analysis to the original informants for reaction, discussion, clarification and confirmation. A total of eight caregivers participated in two focus group discussions. The group discussions were audio taped, transcribed verbatim and included in the data analysis of the current study.

## Data Analysis

Secondary analysis of the original data was conducted using grounded theory techniques for qualitative data analysis to uncover the meaning that the women attributed to their caregiving. This led to an understanding of their actions and interactions with formal providers, as well as the consequences of their actions. Secondary analysis enhances the original study's contribution to overall knowledge in a cost-effective manner (Jacobson, Hamilton & Galloway, 1993), while limiting competition for access to vulnerable study populations (McArt & McDougal, 1985).

It is acknowledged that the present study differs from a grounded theory study in several ways. The analysis of secondary data precludes the concurrent collection and analysis of data, as well as sampling guided by the data analysis, which are hallmarks of the grounded theory method. However, data collection for the original study involved a review of the content of each interview prior to subsequent

interviews. Additional questions were also developed for ensuing interviews to allow the informant to clarify or expand on comments made in a previous interview, or to respond to ideas put forward by other informants. In addition, focus groups conducted for the current study enabled participants to confirm and elaborate on preliminary analyses of their earlier interviews.

Data analysis was carried out on the tape recordings, transcribed interviews and focus group transcripts. Coding and memoing procedures (Straus & Corbin, 1990) formed the basis for the analysis. The Ethnograph (Seidel & Clark, 1984) computer program was used to facilitate the coding and analysis of the data. Preliminary analysis involved reading all of the interviews with each informant and developing a personal profile of each caregiver and her care recipient. The transcripts were analyzed in relation to the original research questions using line-by-line content analysis. Concepts identified in the analysis were categorized and sub-categorized according to similar dimensions and properties of dimensions. As the analysis proceeded, new categories continued to emerge. Similarities and dissimilarities in caregivers' experiences were noted, and possible relationships explored. Definitions of all subcategories were developed, using the original words of the informants whenever possible. As the major themes emerged, the data were recoded to ensure consistency. Memos and diagrams (Straus & Corbin, 1990) were used throughout the analysis to record the researcher's thoughts and questions about the data as they occurred, and assisted in the identification and exploration of similarities, differences and possible theoretical relationships within the data. As the analysis continued, the

paradigm model of Dimensional Analysis (Robrecht, 1995; Schatzman, 1991) assisted the researcher in uncovering the theme most salient to the central action of the caregivers. A supporting theme was also identified as well as the strategies employed in relation to each.

The purpose of the focus group discussions was to discuss preliminary findings with the original informants. Refer to Appendix B for the guiding questions used. The comments of the focus group participants provided validation for the conceptualization of the central and supporting themes of the analysis, and helped to clarify the dimensions of the central action of the caregivers. No new categories or relationships emerged from analysis of the focus group data.

## Rigor

Issues of rigor specific to this study will be discussed according to criteria proposed by Sandelowski (1986): credibility, fittingness, auditability and neutrality. Credibility of this study was enhanced by using the focus group discussions to verify and seek clarification of findings from the secondary analysis. Regular discussions with the thesis supervisor to discuss the coding and clustering procedures, and documentation of personal reflections in memos assisted the researcher to identify biases and enhanced the credibility of this study. In the focus group discussions, participants were encouraged to express all opinions, including those that were different from others in the group, in order to avoid the introduction of bias.

Fittingness is achieved when findings are grounded in the life experiences of the participants and include both typical and atypical elements (Sandelowski, 1986). In

this study, the experiences of all participants are reflected in the findings. Although the volunteer sample solicited in the original study is biased by virtue of self-selection, it was appropriate for this study because it facilitated the identification of individuals with the range of knowledge and experiences that are the focus of the present study (Morse, 1991).

Auditability of a study is achieved when another researcher can follow the sequence of decisions made by the investigator, and arrive at comparable rather than contradictory conclusions (Sandelowski, 1986). All documentation related to the study, including the coding using Ethnograph (Seidel & Clark, 1984), definitions, memos and diagrams are retained for future audit purposes. Consistency was also enhanced by regular coding checks and discussions of findings with the thesis supervisor, who is familiar with the data.

Neutrality refers to the absence of bias in the research process and outcome (Sandelowski, 1986). In the present study, neutrality was achieved through measures used to ensure the fittingness, credibility and auditability of research findings.

## Ethical Considerations

Both the original study and the present study received separate ethical clearance from the University of Alberta Joint Ethics Review Committee. The consent form used in the original study (Appendix C) included a clause which stated the possibility of secondary analyses in the future, pending ethical approval. The caregivers who participated in the focus group discussions signed consent forms before the discussion began (Appendix D).

In addition to protection of the informants, the rights of the original investigators and the secondary researcher were addressed. A letter of agreement between the original investigators and the secondary researcher was written to address issues of data ownership, publication rights and participant anonymity and confidentiality.

# Chapter 4

## Findings

Analysis of the caregiver interview and focus group data revealed descriptions of the women caregivers' perceptions of formal support as they cared for an older cognitively impaired family member. Variations in the womens' perceptions of formal support, changes in their perceptions over the time that they were caregivers, and factors that contributed to those differences were identified. A core theme, keeping the vigil, and a supporting theme, preservative caregiving, provided the best explanation for the womens' caregiving actions and their interactions with formal health care providers. Analysis of the focus group interview data provided confirmation of the presence of the core and supporting themes, and the caregiver strategies related to each.

### Sample Description

Of the 20 caregivers in this study, 9 were daughters of the care recipients, 8 were wives, 2 were daughters-in-law, and 1 was a granddaughter. The women were between the ages of 37 and 71, and had been caregiving from 1 to 20 years. The education level of the women included post secondary (13), high school completion (2) and less than Grade 12 (5). Income levels of the women included less than $20,000 (3), $20,000 to $40,000 (7) and more than $40,000 (10) annually.

Of the care recipients, 12 were male and 8 were female. Nine care recipients were reported to have Alzheimer's disease, five had vascular dementia, three were described as having senile dementia, and three had an unknown cause of cognitive

impairment. When interviews with the women caregivers commenced, 12 care recipients were in nursing homes, 7 were residing with their caregivers, and 1 lived in her own home. At the completion of the interviews, 12 care recipients were residing in nursing homes, including 3 care recipients who had moved from their home into a nursing home during the study. Five care recipients remained at home with their caregivers, and 3 care recipients were deceased.

Sources of formal support were present at individual, organizational and system levels in this study. Individual formal providers included health care providers such

as physicians, nurses, social workers, physical therapists, occupational therapists, personal care attendants, dentists, pharmacists and optometrists. Formal providers at the organizational level included hospitals, nursing homes, Home Care, personal care and home support agencies, and other community resources such as the Alzheimer's Society and religious groups. Finally, references to formal support at the system level were related to the structure and function of the health care delivery system.

## Major Themes

The caregiving situations of the women in this study are diverse. However, despite the idiosyncrasies of the caregiving situations, common themes emerged during the analysis. The core theme was *keeping the vigil*. A secondary supporting theme was *preservative caregiving*. An introductory overview of each theme is provided initially, followed by more detailed discussion of the influencing factors pertinent to the themes and the strategies employed in relation to each theme. The

womens' perceptions of satisfaction/dissatisfaction or consequences of interaction with formal sources of support are integrated throughout.

During the analysis, *keeping the vigil* emerged as the central theme which seemed to encapsulate the main concern of the women caregivers. Throughout the interviews, the women described their actions of "checking", and watching over the cognitively impaired care recipient. One of the women described her caregiving as "a long vigil". Webster's Dictionary (1980) describes the noun *vigil* as "an act or period of watching or surveillance" (p. 1295); and the adjective *vigilant* as "alertly watchful, esp[ecially] to avoid danger" (p. 1295). The term *vigilance* is also described as synonymous with *care* (Roget's College Thesaurus, 1978, p. 57).

For the women caregivers, keeping the vigil essentially involved a continual attempt to find out "what is going on here". They wanted to have a regular picture of the care recipient's health and what they were experiencing. Thus, keeping the vigil involved a constant gathering of information that enabled the women to know what was happening with the care recipient. The women gathered information using a variety of strategies, and used the information to assess the care recipient's health status, to evaluate the care given, to examine alternatives, and to make choices and decisions regarding the care of the family member. As the analysis progressed, it became apparent that the action of *keeping the vigil* most accurately described the women's own caregiving actions; as well, it formed the basis for most of their actions and interactions involving formal providers. Thus, *keeping the vigil* emerged as the core concept which seemed to provide the most fruitful explanation of the meanings

the women attached to their interactions with formal health care providers, and how they subsequently described a given event.

A supporting theme which emerged during the analysis was *preservative caregiving* which involved preservation of the "personhood" or "former self" of the care recipient. Most of the women began their caregiving vigil with the realization that the family member was no longer able to make appropriate judgements and decisions independently, and that they needed to begin acting on the care recipient's behalf. The desired outcome of preservative caregiving was the protection and maintenance of the health and capabilities of the family member. The women also placed a high priority on the dignity and quality of life of their family member. Two categories of preservative caregiving strategies were employed: a) attending directly to the physical, psychosocial and emotional aspects of care of the family member, and b) accessing formal sources of support when needed. When seeking formal support, the women encountered both facilitating and non-facilitating factors that influenced their interactions with formal providers. Influencing factors were described in two main contexts: the caregivers' perceptions of themselves in the caregiving role and their perceptions of the cognitively impaired family member. As preservative caregivers, within the context of these influencing factors, their interactions with formal providers were described in a range of terms that included "collaboration", "getting along", twigging" and "fighting/struggling". Table 1 provides a guide to the discussion of findings.

Table 1

Overview of Themes Portraying Caregivers' Perceptions of Formal Support

| |
|---|
| Influencing Factors |
| Caregiver's Perceptions of Self in the Caregiving Role |
| Caregiver's Perceptions of the Care Recipient |
| Keeping the Vigil |
| Checking |
| Searching for Information |
| Seeking a diagnosis |
| Information about the care recipient's health condition |
| Legal/Financial information |
| Information about accessing the health care system |
| Support groups |
| Preservative Caregiving |
| Personal Care of the Care Recipient |
| Accessing Support from Formal Providers |
| Collaborating |
| Getting Along |
| Twigging |
| Fighting/Struggling |

A more detailed discussion of the influencing factors, core and supporting themes will now be presented. Initially, the influencing factors will be discussed in terms of the two contexts to which they refer. Discussed next are the core theme of keeping the vigil, using checking and information acquisition actions, and the supporting theme of preservative caregiving, which includes both direct care of the care recipient and multiple strategies in interacting with formal providers.

## Influencing Factors

As the analysis progressed, it became apparent that the womens' vigil as preservative caregivers was influenced by two main factors: the caregivers' perceptions of themselves in the caregiver role, and their perceptions of the cognitively impaired family member.

Caregivers' Perceptions of Self in the Caregiving Role

The womens' personal perceptions of their caregiving role were influenced by their philosophy of life and special knowledge of the care recipient. They also incorporated perceptions of family members, formal providers and scarce health care resources.

Most of the women described a philosophy of life that included a keen sense of filial responsibility toward their family member. They believed that it is important that families take care of "their own" for as long as possible. The caregiver's previous relationship with the family member also influenced caregiving. For some caregivers, particularly the daughters, daughters in law and granddaughter, caregivng provided them an opportunity to reciprocate, and to recognize the contributions made by the elder in earlier years. Other women spoke of a strong marriage commitment, believing that their spouse would do the same thing for them. One woman emphatically stated that being a caregiver for her husband was *not* a duty; this was something that she wanted to do. Women who described a conflicted relationship with the care recipient in the past also described a keen sense of filial duty; however, they tended to describe their caregiving role more as a "obligation".

Each of the women brought to the caregiving role a "special knowledge" of the care recipient. Because they knew the family member before cognitive impairment occurred, they viewed themselves as the most appropriate person to preserve the "former self" of the family member. Several of the women felt that they knew how the care recipient would "want things done" when they could no longer make their

needs known to others. Indeed, many of them believed that they could take the "best" care of their family member. One caregiver explained:

> ...I'm the only one around that is really close to my mom, that knows her....What if I was in that same position and I didn't have anyone around that really...cared about me...knew the way I used to be...and would do all the little things to keep some of the dignity around?

The keen sense of responsibility that motivated the women to become caregivers was usually self-imposed. However, several of the women were also influenced by their perceptions of others' expectations of their role. Some of the women stated that the care recipient also expected them to take on and continue in the caregiving role. They described manipulative behaviors used by the family member to ensure that the caregiver continued to care for them. Some women also felt that their family members expected them to take on and continue in the role of caregiver. This made it more difficult for some of the women to request help. One woman described her fear of being "disowned" by other family members if she did not continue to care for her husband on her own.

Other women described how their perceptions of the expectations of formal providers influenced their role as caregiver. Some of the women described their reluctance to request formal help, based on how they thought formal providers might respond to their requests. One woman perceived that formal providers would interpret her requests for help as "shirking her responsibilities". Another woman described her need to have a good "track record" before asking for formal help; that is, she felt she

needed to demonstrate to the formal providers that she had already done everything she possibly could for her family member before asking for their help. Some women described the perception that nursing home staff thought they should be doing "more" for their family member, and described doing things for the care recipient that they perceived the staff expected them to do. Perceptions of societal expectations of women also influenced the caregivers in their role. For example, one woman believed that physicians expect women to "be there" for their husbands.

Nearly all of the women indicated that they believed that health care resources are scarce and should be administered prudently. They also felt that those who needed help most should receive it. This belief seemed to create some hesitancy in seeking help; there was the perception that there were others who needed a given type of support more than they (caregiver/care recipient) did. Consequently, the women sometimes decided not to seek a given type of support for that reason; or, in some cases, waited until a crisis occurred before requesting a given type of support.

For some women, the perceptions of self or others that they should be able to manage alone influenced their willingness to access formal and informal sources of support. Some of the women felt they should be able to manage on their own; it was difficult for them to admit that they could not. One woman stated: "[It's] not quite failing, but it's not winning either." Requests for formal help usually meant the loss of some privacy. One woman explained that her reluctance to seek help likely stemmed from her personal philosophy that family problems are "kept in the family". It seemed that when the women were uncertain of what their role as caregiver

"should" include, it was more difficult to ask for help. One woman described the conflict she encountered when trying to determine what help she should ask for without losing her self-esteem, which had developed from years of self-reliance. Other women described asking for formal help as a "last resort". Interestingly, a few of the women also described the perception that because outwardly, they gave the appearance of managing well on their own, they were much less likely to be offered help from others, even when help was desired.

> C: ...when I go out I guess I look as though I have all my ducks in order...so I guess people don't think that I'm yearning and crying for help inside....one person from the church [said]...'you're always so calm' amd I [said] 'well, yeah' - little did they know what's inside.
>
> I: So what they noticed about you was that you were calm.
>
> C: Yeah, so I didn't need any help sort of thing.

Related to their perception that they should be able to manage alone was a reluctance to request help for themselves or to relinquish their caregiving tasks to formal providers. Several of the women stated that it was more difficult to request help for themselves, or help that would involve relinquishing their "duties" or roles. In particular, the experience of placing a family member in an institution left several of the women "uncomfortable" with the transition. They asked themselves "What do I do now?". In other words, they wondered what their role as caregiver would be, now that the family member was insitutionalized. For some of the women, a change in their roles or in the caregiving relationship was viewed as a loss. One woman

described her experience of ceasing to do laundry for her mother, who resided in a nursing home:

> C: ...they [nursing home] have taken one more responsibility off - I was trying to do my mother's laundry...so every time I would pick her up it would be hurry home, get the laundry in, get it done, so when we would go back my mother and the laundry would go back at the same time, and the director said 'why don't you let us do the laundry and then you won't have that sort of compulsion to do the laundry because she's going to run out of clothes?'...and in one way it's freed me but it's also meant that I'm not there on Monday because I know she's going to have clean clothes....there might be many people left with that sort of 'What do I do now?'
>
> I: Did you feel a sense of relief when that was taken on, or a sense that this was the last thing you did for her and now that was taken from you?
>
> C: ...well I don't resent it, but suddenly I realized that I'm not there on Monday's - I'm not making the effort to go there and the Monday's have just kind of slid by. So they've made it easier not to go...

Caregivers' Perceptions of the Care Recipient

Characteristics of the care recipient seemed to influence the womens' approach to providing direct care and their strategies for seeking assistance from formal providers. One dimension described by several of the women which seemed to impact their caregiver role was the care recipient's "awareness" of what was happening. For example, many of the women described a period of time in which they felt that the

family member was "aware" of the fact that they were declining cognitively, but still strove to continue on as they had been. During that time, they found that the care recipient was more resistive to receiving assistance from others, even the caregiver. This was stressful for the women because the care recipient's awareness made it difficult for the caregiver to maintain as close a vigil as she wished. The women felt that they had to watch the care recipient more closely without making the care recipient aware that they were being watched; awareness which could result in a loss of dignity and esteem for the family member. This woman described how differences in her mother's "awareness" over time affected her caregiving activities:

> ...There's been lots of changes because...at first she was very resistant to being 'taken care of', and it was a constant struggle...I had...more than enough to do with making meals and taking them over and making sure, you know, she was looked after....it was very frustrating, and it's a paradox - as she's gotten worse, it's gotten easier to take care of her....Those first few years were horrible because she was still aware enough to be frustrated, angry...and yet strong enough to resist interference, so since then it's been a dramatic change...

Several women described their family member's denials that anything was wrong, and their attempts to "cover up" their loss of ability. Indeed, a few women noted that the cognitively impaired family member's outward appearance of "normalcy" made it less evident to others that anything was wrong, or that the care recipient had special needs. Other women described manipulative behaviors of the

family member, such as pleading, crying, and "guilt trips" to keep the caregiver caring for them. Some of the women found that they could not care for the family member in their own home because of the conflicts that occurred between the care recipient and other family members, such as the caregiver's husband and children. One woman described her feelings of guilt as she came to the relaization that she could not care for her mother at home:

> ...and my Mom kept saying through all of this 'We never put our people into a nursing home'....that was a very pointed message to me...I knew that she was trying to make a point. And I felt like--'What am I going to do?' My Mom is expecting me to look after her, she's depending on me. And my family are telling me they don't want me to look after her. So 'What am I going to do here?', you know.

Because the cognitively impaired family member also had difficulty trusting others, particularly strangers, one woman described her husband's fear that people were stealing his things. Several of the women found that they could only access help that was "acceptable" to the care recipient. One described "talking [the care recipient] into accepting certain kinds of help". Another caregiver described the difficulty she encountered when trying to access help from the health care system for her cognitively impaired mother:

> The thing that was frustrating for me is that in order to really get my mother on the system, she would have to sign the forms, which of course she would refuse to do because she doesn't need any help in her mind...she's going to

> stay in her own home and 'thank you very much but get out of here'. And so there is nothing I can do to have forms in progress should something happen to her...There is nothing I can do unless I...drag my mother into court, get guardianship against her will and then I can sign the forms....I'm unwilling to force her to have anything to do with any such process. I choose not to fight with her on this issue....If a crisis happens, well that's just the way it is.

In the later stages of caregiving, when the care recipients were less "aware" of what what happening, it became easier to access help because the care recipient was usually less resistive. However, the caregivers encountered problems when the care recipient became unable to communicate with others. Several women described how difficult it was to ensure that the needs of the care recipient were being met when it was so difficult to assess, for instance, if the care recipient was in pain.

Another characteristic of the care recipient that specifically impacted the womens' strategies employed in presevative caregiving to access help from formal providers was the difficulty in knowing when a given type of support would be needed. This difficulty was associated with inability to predict the specific form or timing of the care recipient's expected deterioration in function. This dimension was particularly relevant for the caregivers whose family member had Alzheimer's type dementia, which is characterized by an unpredictable course of deterioration. Although some of the caregivers of Alzheimer's victims placed their family member on a waiting list for placement early in the caregiving experience, knowing that placement at some time in the future was inevitable; they still asked themselves "How

will I know when it is time?". The women did not want to place the family member in a nursing home before it was necessary, therefore they wondered what utimately would cause them to seek placement. Consequently, some of the women stated that they lived "one day at a time". This was stressful for the women; as one woman stated "living without knowing is not easy". The unpredictability of the course of Alzheimer's disease also impacted requests for help on a day to day basis. As one woman explained:

> ...I'm not good at asking for help. But [help is] not something you can ask for with [Alzheimer's dementia]...because you don't know if you're going to have a good day, bad day, mediocre day....You just don't know...

Several of the women also stated that they believed that their family member must be "very difficult" for the formal providers to care for. The women cited many characteristics of their family member such as: the tendency to wander or be verbally abusive toward staff, and inability to perform any self-care activities, that they felt made the formal provider's job a difficult one. As a result, some of the women tried to decrease the impact of such characteristics on the formal provider. For instance, one woman decided not to send her husband to the day program on days that she knew the day program was taking the care recipients on an "outing"; she felt that her husband must be "one of the worst" to care for because of his tendency to wander away from the group. This woman was also concerned for her husband's safety, should he wander away. One woman described the circumstances by which her acutely ill husband was discharged home under her care. She was certain that her

husband had been discharged home in an unstable condition because he was a very difficult person to care for, and that hospital staff had been "only too happy" to shift the responsibilities onto her. Another woman described how she tried to placate formal providers who had been verbally abused by her husband:

> ...the attendants get upset if [care recipient] is short with them, and so...alot of your time is spent just acting as a little go-between...hoping everybody will get along with everybody...

Several women commented that formal providers as well as members of the public lacked understanding of cognitive impairment and of the special needs of cognitively impaired people. The women felt that the health care system attended more to the needs of people with physical (as opposed to mental) problems. They felt that most long term care facilities were devoted to the needs of the physically disabled; as a result, they perceived that there were fewer appropriate care alternatives available to them. One woman stated that because of this, cognitively impaired people "end up" in nursing homes sooner than they need to. The women also felt that many people tend to be uncomfortable around cognitively impaired people; they are uncertain how to be helpful. One woman felt that the general lack of understanding of mental disabilities seemed to make cognitive impairment a moral issue; she perceived that people with mental disabilities were expected to "smarten up" or "snap out of it".

Some women felt that because of the lack of understanding of cognitive impairment, there are fewer people who are interested in working with cognitively

impaired individuals. An example given by one of the women was that there were few volunteers who were willing to work with cognitively impaired people; volunteers tended to spend more time with people who they thought would benefit more from a given activity. Another woman felt that she and her husband received fewer visits from people at their church for the same reason. Many of the women felt that because of the lack of understanding of cognitive impairment, the care recipient and caregiver were at greater risk for isolation, particularly those still living in the community. Another consequence was that the women tended to take on more responsibility for ensuring that the care recipient received adequate opportunity for social interaction and stimulation.

## Keeping the Vigil

Most of the women wished to act as an "ombudsman" for the care recipient, based on their perception that the cognitively impaired care recipient needed someone to look out for them. Keeping the vigil involved two closely related strategies of "checking" the care recipient and searching for information from other sources as they sought to act on behalf of the care recipient. The women described "checking" activities that they used to become and stay informed about the care recipient's situation. Many of the women stated that it was important for families to do this, as "families know the care recipient best", and only families notice the subtle changes in the care recipient's health. Their ability to notice the subtle changes in health come from their special knowledge of the care recipient, based on an extensive prior relationship with that family member before a decline in health occurred. They used

specific information acquired through their continuing vigil and use of checking activities as the basis for their advocacy on behalf of the care recipient. Although most of the "checking" strategies were used in the context of a care recipient who lived in an institutional setting, some of the women also engaged in checking activities within their own homes prior to the care recipient's institutionalization.

In addition to checking, information was sought using other methods and sources in relation to caregiving issues such as seeking a diagnosis, understanding the care recipient's condition, obtaining legal/financial information, and information about the health care system. The women had divergent perceptions of the utility of support groups as a source of information.

The womens' information-gathering techniques were both overt and covert. When the women actively sought out written information about the family member's health condition, and asked questions, their information gathering was overt, or readily observable by others, including health care providers. However, the women also spent a great deal of time watching; observing the care recipient, watching for changes in health status, watching the care provided by formal providers, and observing to see that the family member was receiving the needed care. While all of the women were involved in the more overt information gathering activities, it was the women whose family member was being cared for in an institutional setting who most often engaged in the more covert, observational methods of information gathering.

Keeping the Vigil: Checking

The caregivers' use of checking strategies were influenced by whether the care recipient lived with the caregiver or in an institutional setting. Two women described their use of checking when their mothers lived on their own in the community, prior to their admission to an institution. One of the women described her caregiving/checking activities as much more stressful prior to her mother's admission to an institution. Part of this stress seemed to be related to the fact that the care recipients were still living on their own, even though each of the care recipient's cognitive impairment was evident to the caregiver. Both women described concerns that their mothers were not eating properly. Another concern was the care recipient's loss of the ability to manage finances independently; one woman described how the care recipient's money kept disappearing, and the care recipient was unable to remember how the money had been spent. The caregiver was unable to monitor the care recipient as closely as she felt was necessary to ensure safety and preserve health. The women seemed very conscious of the need to maintain the care recipients' dignity, and therefore they tried to keep their vigil as unobtrusive as possible. The other aspect that was stressful for these women was their perception that they were on their own in their vigil. There seemed to be no help available to them, the care recipient was "too well" (physically) to be in a nursing home, yet their cognitive status put them at risk for losing their physical health and safety.

For the women whose family members were in an institutional setting, checking activities were also aimed at ensuring that the physical and emotional needs

of the care recipients were being met. Therefore, many of the caregivers visited their care recipient on a regular basis to monitor their health status. The women valued their own observations, often stating that they "wanted to see for themselves" how the family member was. Sometimes the women used the information obtained from their observations as a basis for seeking additional information. Several of the women sought information from the formal providers, either to substantiate or to complement the observational information they had already gathered. Caregivers occasionally asked the care recipient questions about what was happening, however, this was not always possible, because of their cognitive impairment. When the women encountered difficulties in acquiring information, they often responded by intensifying their checking strategies. Sometimes the checking strategies became more covert. Even when caregivers found through their checking that everything was alright with the care recipient, the checking activities continued. One woman described why she visited her mother at the nursing home on a regular basis:

> I need to go; I need to see that she's alright. I want to be sure that there isn't something else that I can do for her, and I have to check that out....I would say it's more for me personally....But I just want to see her you know. Just in case there's something - or maybe one day...she will be talkative, so I have to kind of be there if that change does occur. Or if she does get really sick and needs somebody then I won't know if I'm not sort of keeping a check So I want to do that. No, I couldn't live with myself if I didn't know every week that she's sort of o.k.

Another woman was much more pointed in her motivation to monitor her mother in the nursing home: "...it's all these things that you notice; we've had enough experience to catch trouble before it happens....we know what to watch for." She used this information to work with staff to prevent problems whenever possible.

While visiting the care recipient in the nursing home, the caregiver made a number of general observations. She would check to see that the care recipient was clean, that their clothes were clean, and that there was a sufficient amount of clean clothes on hand for the care recipient (whether they did the laundry or the nursing home did). Some women described noting whether the care recipient had enough toiletries and clothing. They also checked for clothes or shoes that needed to be mended or fixed. Others checked to make sure that the care recipient had enough money in their purse or "account" at the nursing home to pay for outings or other activities. Some women described checking to make sure that the care recipient had their glasses on, their dentures in, and their hearing aids in place and turned on.

Several caregivers described visiting their family member at different times of the day in order to observe the care that they received throughout the day. Sometimes they would visit at mealtimes in order to see what the care recipient received for meals, and how well the care recipient ate. They noted the times that the care recipient was in bed and out of bed. They conversed with the family members of other residents at the nursing home, seeking confirmation that needs were being met. One woman described a strategy that she used to observe the care provided: "I try to vary my times of day that I go [to the nursing home] for obvious reasons. I don't

want to develop any pattern....I can see care at all levels then."

Several of the women felt that maintaining the physical capabilities of the care recipient was a high priority, and described checking to see that the care recipient was mobilized regularly. One woman stated that whenever she went to visit her mother at the nursing home, her mother seemed to be in bed. Even though staff assured her that her mother was up out of bed regularly, the caregiver felt a need to see for herself that this was so. Even assurances from family members of other residents at the nursing home were not enough for this caregiver to feel certain that this need was being met consistently.

"Checking" was a high priority for the women; however, it was a strategy that was very demanding of their time and energy. Several of the women who were caregivers of institutionalized family members found that they had to decrease the number of visits they made, and to decrease the amount of time spent per visit, as their own energy diminished. One woman, who worked full time, described how she had to "assume things have been good" (ie-that her mother was getting enough exercise with her walker), as she could not physically get to the nursing home as often as she would like to see for herself.

One woman who was herself a senior and caring for her mother, found that it was not physically possible for her to observe her mother as often as she felt was necessary. However, this woman decided to privately hire a "companion" to visit her mother on the days that either she or other family members could not. The companion kept the caregiver informed of "what was going on" on the days that she visited the

care recipient. This was a very satisfactory solution for this woman; she still had access to daily information on the health status of her mother, without the stress of visiting the care recipient everyday.

> ...we have hired help for her [care recipient], as companionship...she's our watchdog too....so she's [care recipient] virtually got somebody dropping in almost everyday....she [companion] contacts us every time [she visits]....So it's almost like we have a daily picture of what's going on. So that works well".

This was the only caregiver who hired a companion for the purposes of helping with both checking and meeting the psychosocial needs of the care recipient; another woman was looking at the possibility of hiring a companion to visit the care recipient also, but it seemed to be more for meeting the psychosocial needs of the care recipient.

Keeping the Vigil: Searching for Information

In the context of formal sources of support, caregivers searched for information in relation to issues arising throughout the caregiving experience. the issues addressed included seeking a diagnosis, understanding the care recipient's condition, obtaining legal/financial information and information about the health care system. Support groups were a source of information with which the women had varied experiences. The barriers encountered and their experience in relation to each area addressed are described next.

The beginning stimulus for the caregivers to initiate their vigil as preservative

caregivers was signs of cognitive impairment in the care recipient. Many of the women began to notice that their family member lacked insight into health issues, and was unable to seek help from others appropriately. The caregiver became an advocate, or ombudsman for the family member at that time.

The women realized that they needed to make decisions about present and future care needs. Many described this as an overwhelming experience; that is, having to make decisions on behalf of someone else. Even though the women frequently identified themselves as the best person to make those decisions, many described their feelings of anxiety and helplessness in taking on such a responsibility, as one woman stated:

> ...it was frightening because...when you're doing something like that you have to put yourself in their shoes also and wonder how you'd feel in the same situation. But yeah, it was really frightening for me...just making decisions for her...hoping it was the best for her.

Seeking a diagnosis. It seemed that most of the women began their vigil by using strategies to obtain information pertaining to the health status of the family member. This information was sought from health professionals in the form of medical diagnoses and/or interdisciplinary geriatric assessments.

For some women, the realization that their family member could no longer manage all aspects of life independently came suddenly in the form of a medical crisis, and their interactions with formal health providers began at that time. Other women caregivers noted subtle changes that occurred over a period of time before

contact with a formal provider was made. Whether the realization came suddenly or gradually, many of the women's first attempts to gather the information that they needed in order to begin to make appropriate decisions on behalf of the care recipient involved seeking an assessment of the family members' overall health status from their physician and/or other health professionals.

The women varied in their sense of urgency to obtain a bona fide medical diagnosis. For some of the caregivers, it seemed that a firm diagnosis was not a priority, and a specific event of going to a physician for an assessment or diagnosis was not described. One woman explained it this way: "I just knew Mom. I thought I did." Some women were given non-specific explanations for the care recipients' cognitive impairment, such as "hardening of the arteries" and "aging". This woman explained her low priority for a "label"; or cause for her mother's cognitive impairment: "...it doesn't make any difference; the results are the same." Another woman was advised by her clergy that her husband may have Alzheimer's Disease two years before her husband was actually diagnosed with Alzheimer's disease:

> ...it was diagnosed unofficially by a clergyman...he had seen many cases of people in his congregation, and he said he was afraid that's what [husband's name] had, but I didn't press the issue. I guess I really didn't want to know and so it was not formally diagnosed until [two years later].

Another woman described her reluctance to seek a medical assessment or advice regarding the family member's behavioral problems, which were distressing her family. She was reluctant for several reasons: She was afraid that the health

professionals would view the problem as insignificant and not worth their attention, she was reluctant to abuse the scarce health system resources and she thought that the care recipient would be required to be an in-patient for assessment. This caregiver feared that the care recipient would deteriorate further in an institutional setting, even for a short period of time, resulting in an inaccurate assessment.

Some women sought a diagnosis because they wanted to determine if the cognitive impairment was related to another problem that could be treated. One woman sought a diagnosis so she could make decisions, but said it was "...three years before they actually wrote it [Alzheimer's Disease] down, so I could get anything in place." For this woman, having a diagnosis enabled her to begin learning about Alzheimer's Disease and to make plans for the future. For the women whose family member experienced a sudden medical crisis, a medical diagnosis and prognosis was usually, but not always, offered. Some women described waiting for diagnostic information to be offered, and finally having to ask for that information. One woman described the worry that she felt when her husband was hospitalized with a stroke; at the time she did not know what was wrong with her husband and she "could not get any information out of the doctors".

It was important for some of the women to perceive that the diagnosis was based on sound evidence, and determined by people qualified to do so. One woman expressed anger and frustration when a nurse informed a family member that the care recipient had Alzheimer's disease. The woman felt that the diagnosis was inaccurate, and was provided by someone who was not in a position to diagnose. Finally, the

woman was upset because she felt that the "label" of Alzheimer's disease prompted the other family member to treat the care recipient like a "vegetable". Even after a diagnosis was provided, the women tended to combine the opinion offered by the health professional(s) with their own knowledge of the care recipient. They evaluated the accuracy and usefulness of the diagnostic "label" or information for their own situation.

Some women sought an interdisciplinary geriatric assessment to determine the care recipients' capabilities and care requirements. They tended to express appreciation for the objectivity of the assessment; feeling that the outcomes of the assessment (ie- determination of care needs, such as institutionalization) were easier for the care recipient to accept also. Some women described subsequently feeling less burden and guilt in making a decision to institutionalize their care recipient.

> ...I'm sort of convinced now that she's had every possible chance to be as independent as she possibly can....you just don't assess a person a certain way without giving them every chance to show what they can do. And then you can sort of live with that, or at least I can because I know it's objective ....that helps me accept the actual decision that it is nursing home or it is lodge. That's not on my shoulders. Because it's hard enough to say 'well this has to be'...I think too the person being assessed feels that it's not family telling them that this is what has to be done.

One woman described how an interdisciplinary assessment of her husband resulted in her being advised that her husband had a tendency toward aggressiveness. Although

she described how this information actually increased her stress, it also enabled her to set priorities for her caregiving - that is, she decided that she needed to keep her husband busy and happy as much as possible. Another woman described how the diagnosis of Alzheimer's disease was helpful to her in explaining her husband's impatient behavior to others. For example, in the grocery store, she found that people seemed to respond in an understanding and helpful manner by letting her get through the line up at the cashier faster.

A barrier to obtaining an accurate idea of what was happening with the family member frequently rested with the care recipient, who often denied that anything was wrong, and refused to go to the physician for an assessment. One woman described her "loss of courage" when she was unable to convince her husband to go to the doctor. Another two years elapsed before she was able to try again - at that time, her husband was diagnosed with Alzheimer's disease: "...so I kept thinking...'Am I imagining these things?'...'Is it me?'....Finally our daughter said 'Dad has to get to the doctor'....I was reluctant to get on the treadmill again. But I did.".

Physicians' attitudes sometimes presented another barrier. Women who were wives of the care recipients, noticed many more "subtle" changes that were not readily apparent to others, even other family members. These subtle changes sometimes were manifested as changes in the family member's personality or mood. One woman described to her physician the difficulties she was experiencing as her husband seemed to become increasingly critical of her. The physician advised her to "learn to live with it, or divorce him". This reply led this woman to feel self-doubt in

her observations, and to avoid seeking medical advice for some time following.

The women often made care decisions based on the diagnostic information. For example, two women whose husbands experienced a sudden medical crisis were informed that their husbands would soon die. Based on that information, and the knowledge that their husbands desperately wished to be at home, both women decided to care for their husbands at home. At the time of the interviews for this study, which occurred years later, both women continued to care for their husbands at home, and commented that the information that they had been given was inaccurate.

The diagnosis, or absence of a diagnosis, also seemed to impact financial decisions made by some of the women. Two women described major financial decisions that were made during the time that they were still uncertain about the nature of their husbands' problems. Later, they commented that those decisions turned out to be inappropriate. Another woman described how her husband's early retirement could have been handled differently and with less of a financial loss if the diagnosis of Alzheimer's Disease had been made earlier. She had attributed many of the changes she had noted in her husband to his diabetes.

A specific diagnosis (of Alzheimer's disease, for example) seemed to facilitate the womens' search for additional information in order to better understand what the care recipient was experiencing, to prepare for what may happen in the future, and also to set appropriate goals for care. For example, women who were offered a diagnosis of Alzheimer's disease usually sought information from the Alzheimer's Society in the form of books, newsletters, video tapes, guest speakers, and so on. It

also provided them with the opportunity to join support groups for caregivers of Alzheimer's victims; to interact with other Alzheimer's caregivers, and to share information and experiences. For these women, the Alzheimer's Society was a very visible resource with a variety of mediums by which the women could gather the information they felt they needed.

Information about the care recipient's health "condition". Many of the women expressed a need to understand the "condition" of the care recipient, whether it was AD or cognitive impairment related to other causes, such as pre-existing medical conditions. They wanted to understand what the care recipient was experiencing, and to gain insight into future needs, problems and issues that may arise over time. They also wanted to make decisions about what their role as caregiver would involve. The women also expressed a desire to learn about the condition of the family member in order that they could be "good" caregiver:

> ...you get into this and you're not ready for it; it happens to you and you're right into it without really anywhere to go to receive [help]; you really need to be counselled along I suppose in order to do a superb job of it....I mean...if you are going to do it [caregiving]...then, you know it's best to learn about it; help yourself as well as the other individual [care recipient].

One woman, on the basis of her reading, increased her efforts to maintain the physical capabilities of her husband by encouraging him to continue to do as much for himself as possible.

> ...they are signs of Alzheimer's disease...I read up alot on Alzheimer's...I let

> him do as much as [he] can by himself, even though it takes longer...I would do it, but I feel this is a therapy for him, every little bit he does is a therapy for him....Also I let him pour the coffee and I noticed this morning...he's very very shaky, he [is losing] his table manners very slowly...we don't say anything.

Several of the women described how they initially increased their level of knowledge through books or other media such as audio or video tapes.

The women's search for information on the condition of their family member was facilitated by their great desire to learn. One caregiver described her need to learn and to understand this way:

> ...then I just started to gather a great deal of material - wherever I saw anything about Alzheimer's...cognitive impaired situations, I just read and read and read. And I sent it to my sister...just like anything in life...ignorance is not really bliss.

Several women encountered barriers to obtaining the information about the care recipient's condition. The women who had a less specific diagnosis, or no diagnosis, tended to search for informational support from support groups and organizations involved with the care of older adults. These women did indeed seem to need to search "harder" for these types of support. Some women found that phoning one potential source of information led her to learn of other phone numbers where she could potentially obtain the information she was seeking.

Some of the women did not describe specific actions to obtain information

pertaining to the care recipient's condition or caregiving issues. One woman described a desire to gain a greater understanding of aging and of caregiving, but did not know where to find that kind of information. She wished that someone would take her aside and offer that information to her. Another woman did not begin to seek specific informational support until she began experiencing difficulties in her relationship with the care recipient (her father). Some of the caregivers did express a need for information/advice that would help them to develop a meaningful relationship with the cognitively impaired care recipient. The barriers cited by these women were a lack of awareness of where to obtain this type of support, and the perception that this support was not offered, and therefore not available to them.

Legal/financial information. After obtaining medical information including a diagnosis and knowledge of the care recipient's condition, some of the women sought information about guardianship, trusteeship and power of attorney. Many of the women were concerned about money for institutionalization and future funeral costs. One woman described her strategy of "phoning around" to get the information that she needed:

> ...I phoned yesterday to the [Society for the] Semi-Retired and Retired and you can get the forms [for guardianship] and do it yourself for $175.00...she gave me the name of a lawyer...so I'm going to get in touch with him and see...I found out that the [Society for the] Semi-Retired and Retired also have a support group for that...you just don't know, I didn't even know that was available until I phoned....So, getting into some kind of a group might help

[lead you] to other things, where somebody else knows something else.

Other women expressed a need to know more about the legalities surrounding life support:

> ...if she gets really sick and has a stroke or something, then how do you handle it so that she's not put on life support for ages....there's that sort of help that you're asking for that...you kind of beat around the bush to get it....I don't think it's readily available.

Another woman attempted to gather the needed documentation that would prevent ambulance and emergency room personnel from resuscitating the family member in the event of a cardiac arrest:

> ...if he [care recipient] asks for an ambulance, I will call it. If I call an ambulance, they will resuscitate him if he has a cardiac arrest because they are obliged to....I'm trying to get the appropriate documentation in place - which you can with some effort - with respect to the ambulance drivers not giving resuscitation....But it isn't easy to get the paperwork together. I've been trying to do that - it's not myself that I'm having difficulty with, or [the care recipient], it's the other people.

Information about the health care system. Most of the women described strategies they used to try to understand the "system". They wanted to know what kinds of help were already in place that may be helpful to them at some point in their caregiving experience. One of the challenges described was finding out where the help could be obtained. One of the women described her actions as "getting to the right

person with the right concern". Information that was offered to the women to help them to understand the system was generally perceived as helpful and satisfactory by the women. However, most of the women seemed to have to ask for this type of information. The perception that the information was not readily available tended to increase the womens' feelings of stress. One woman described how the friendliness of the people she spoke to increased her comfort level in seeking help, and her satisfaction with the eventual outcomes:

> I found...individually, the institutions that I went to...they were wonderful. They were really fine. And also when I went to look at [nursing home], the people there were just great and I went several times because you want to make sure you're doing the right thing....the people that you dealt with were really nice; you felt real comfortable with them....at the Central Registry, I've never met the lady, but she was wonderful on the telephone to me....I felt very comfortable phoning her.

One caregiver described how the staff at the day program that her mother attended offered her information about different types of help that are available in the community, such as respite programs. This woman commented that there are likely a lot of programs and services available that would be helpful to the caregivers, but a significant barrier to caregivers accessing such services, she felt, was a lack of awareness of what was available.

Several of the caregivers described difficulty accessing the information they felt they needed. The difficulties they encountered often related to a lack of

understanding of where to access the needed information and created the perception that the information was not readily available. The situation most commonly cited was a lack of understanding of how the system works with respect to obtaining long term placement/continuing care. One woman described her strategies to obtain the information she needed as a "seek and ye shall find" method. The strategy of "phoning around" seemed to be used by many of the caregivers in order to eventually find the information that they needed. One woman commented that making one phone call to seek a certain piece of information led her to obtain phone numbers of other potential sources of information. This woman described how she would persevere in her search for needed help:

> If I desperately [needed] help, I would ask...when I needed the bed for him, I did ask...when I needed the commode, I did ask...If I need something for my husband in any way, I [would] not hesitate to ask and I [would] search for the place [where I would] get some support or help.

However, seeking information in this hit and miss manner was particularly stressful for those women whose family member experienced a sudden change in health, or in the ability to function independently. A sudden change in the health of the family member necessitated immediate decision-making regarding future care. This meant that the caregiver had to obtain the needed information in a much shorter time frame. One woman commented that there did not seem to be one place or person that she could go to in order to gather the information that she felt she absolutely had to have in order to make decisions regarding placement of her mother into a nursing

home. This difficulty in obtaining information about the system added to the stress this woman was already experiencing by virtue of the sudden change in her mother's health and being suddenly thrust into the position of having to make decisions "for" her mother, who was previously independent. The "background work" of gathering information was greatly impaired in this situation. Not only did the woman have less time to gather the information she needed, she also had less time in which to examine and evaluate the alternatives and make her decisions.

One woman attended an orientation session on elder care for caregivers. She found the information provided was helpful to her; she felt better prepared to deal with the process of instutionalization of her family member. She stated she would recommend the program to others who were beginning to provide care to older family members, as it prepares caregivers for events that they may otherwise find "shocking" and upsetting.

> They have those little courses that you go to...to train on how to deal with...elder care...It's well worth every minute of it to go and find out what's required, and not be surprised at the system and how callous it may seem.

Another caregiver, who was in an administrative position in a longterm care facility, described herself as having an "in" as far as understanding how the system works, and in knowing which nursing homes provide the "best care". However, this woman found herself in the unique position of trying to help other caregivers to understand "the system". Because of this experience, she concluded that the system needed to be changed: "...there's got to be a better way to help people. I mean it's

just not right that you have people sobbing on the phone or sobbing in your office over a system. I mean it's just terrible."

Another barrier encountered by the women as they sought to examine alternatives and to make appropriate care decisions for the cognitively impaired family was the inability to predict how the care recipient may deteriorate over time. This meant that even though a caregiver was able to obtain the information she needed to understand the system, there was still some uncertainty experienced regarding "when" and "what types" of help may be needed in the future.

Support groups. Support groups are a potential source of information about caregiving issues that were accessed by many of the women. Although the women's experiences with support groups are quite diverse, there are some similarities. Initially, the women who attended support groups did so in order to obtain information about the family member's "condition", and also to learn how to manage the problems that they were encountering as caregivers. However, the women who continued to attend support groups throughout the vigil seemed more interested in the aspect of sharing similar experiences and humor with other caregivers, and in the affirmation that they recieved from other group members.

Other women described the barriers that they encountered that prevented them from accessing support groups as a means of learning about the care recipient's condition. Examples of barriers included a lack of awareness of how to access a support group, caregiving activities that made it difficult for them to get away or to find time to attend, geographical barriers, and an inability to obtain the specific

informational support desired. The womens' descriptions of their experiences with support groups revealed the presence of both facilitating and non-facilitating factors which impacted each woman's perception of the support she received.

Several women described finding a support group that would address her informational needs as the first step. For the women whose care recipient had a diagnosis of AD, the Alzheimer's Society was a visible resource that these women initially turned to for informational support; the diagnosis seemed to facilitate the womens' search for information. However, most of the care recipients did not have a specific diagnosis of AD. Several of the caregivers described seeking informational support through other support groups offered in the community. It seemed that when the care recipient had a less specific diagnosis, the women spent more time looking for a suitable support group. One woman described how she found a support group on elder care offered by the city's health department:

> ...I found them because I felt that I needed help myself...during one of the times that [care recipient] was sort of giving me a rougher ride than he gave anyone else, or that was my perception....So I just started calling the [name of city] looking for something that could lend support or help to me and that's how I found this parent support group.

Other women described the support groups available to them at the nursing home in which their family member resided. One woman described her involvement with two different support groups located in nursing homes. She found that she preferred to attend the support group in one because she felt that the issues and concerns discussed

in the group were more closely related to the issues she was experiencing. She also received phone calls from other group members to inquire how she was doing, and to invite her to attend upcoming meetings. The meetings were held on a regular basis. The consistent invitations to attend seemed to be a major facillitator for this woman's participation in the support group:

> There's [a meeting] today at 1:30, and I go to [nursing home] and they still ask me to come back there, so I go faithfully, because I've only been invited to one at [other nursing home]....the group [is] consistent, they phone me all the time, talk to me, ask me how I'm doing....so I was invited to keep on going, so I go.

This woman also believed that if she did not attend after being invited a few times, the invitations would likely stop.

Another woman who was caregiver for her mother-in-law commented that a support group could be a potential source of support to her. This woman expressed her difficulty in requesting this type of support. She wished direction would be offered to her.

> Maybe there are other people out there that feel...many of the same things I'm feeling...that I could identify with and...would get help from, but I'm not in a group, you know...I'm not aware of something like that....I think probably I could use a little more direction....about--you know, the quality of the time [spent with the care recipient]....you get in a rut after a while....Now if I had some direction telling me that yes, this does make a difference, and yes, this is

> normal...and yes keep on doing what you're doing...then maybe I would feel happier and I would maybe change [my caregiving actions] a little as well.

Lack of awareness of how to access help from a support group was only one of several barriers that a number of the women faced. One woman described geographical barriers to attending a support group, related not only to the distance she would have to drive in order to attend a meeting, but also having to deal with poor driving conditions in the winter months. Several of the women cited caregiving duties that prevented them from attending a given support group regularly, if at all. For example, two women described themselves as caregivers not only of their older family member, but also of their children. They could not find the time to attend support group meetings. One woman expressed her surprise with an interview question regarding her involvement with outside organizations (such as support groups):

> That really surprises me; I would be surprised if caregivers had time. I don't have the time....I belong to no clubs and to no groups...it's not because I don't want to, I just don't have energy or time."

Other women described their reluctance and/or inability to leave the care recipient in order to attend a support group meeting. This was particularly relevant for the women who were caring for their family member at home. Some of the women found that there was no one who could stay with the care recipient in the home while the caregiver went to the support group meeting. For two of the women, part of their inability to attend was related to their husbands expectation that the role

of the wife was to be with them. One woman, who was unable to attend support groups for both of these reasons, commented on the types of support that she would likely receive from a support group:

> ...if you were asking what help care people need...I think it is important [to] have their support group [so] they can see that...these things [care recipient behaviors] are common...so they can laugh together and and say "well, my mother did this and isn't that funny; they don't know each other but they're doing the same things'. Then that person can go home that night...and kind of smile to herself while [the care recipient] is throwing the lamp or whatever and say 'well, I guess it's happening across the street in the other house too; this is not just some terrible thing that is happening to me'....I never thought I'd ever say that a person would really need to rely on...those little support groups, but actually I think it's not a bad idea, because your friends will leave and your family will grow weary of it and people won't understand, but the people who have the same situation will understand...

Another woman whose mother was residing in an institutional setting described how she had to make a decision whether to continue attending a support group, or use that time with her mother. This woman found that the support group was not meeting her needs for information as she had hoped it would. By reading on her own, her knowledge level had surpassed that of many of the other group members. She found that she was spending her time at the support group helping other members to 'understand"; she described the group as moving too slowly, and eventually decided

that spending the time with her mother was a higher priority for her.

Much of the information the women gained in support group situations related to changes that may occur over time, and issues that may arise in the future. This seemed particularly true for the caregivers of Alzheimer's victims. Many of the women described a need to learn how to deal with issues that they were already encountering in their caregiving experience, but some of the women encountered difficulty when attempting to obtain solutions to their current problems. Part of the difficulty was related to the uniqueness of each caregiving situation, and the changes which occurred in the care recipient over time. Again, this seemed to be a conflicted source of support for some of the caregivers, as it was difficult for them to apply the experiences of others to their own situation. One caregiver described her frustration when she and others in the support group tried to get "practical answers" or specific suggestions to deal with the problems they were encountering.

> ...I found it frustrating at first going to the Alzheimers meetings because nobody has the answers that you yourself are looking for....Nobody has the answer as to how you're going to get your husband into the bath tub next Thursday morning....So I came home lots of times frustrated because I heard people asking for help, pleading for help, but nobody had the right answer...I think it's just something that you have to sort out for yourself, and by talking to other people and finding out what they did and putting other ideas together you can sometimes find your own answers, but this is such a frustrating disease in itself...when you can't get the answers that you really think you

absolutely have to have in order to survive...it makes it more frustrating.

Information regarding possible future issues seemed to be a source of conflicted support for some of the women. On the one hand, they wanted to know what issues they may face; but at the same time the women were aware that not everyone experienced the same issues and concerns. When they heard the stories of other caregivers and the issues/problems they were encountering, the women would describe going away from the meeting wondering (and worrying) if they too would encounter that same problem. The inability to predict the course of the disease in terms of the problems that individuals encounter and also in terms of how quickly or slowly changes will occur also seemed to add to the stress level of some of the caregivers.

> ...on the other hand, you also become alarmed by other people's stories; you hear about other [care recipients] who get up at 2 or 3 in the morning and demand to go out for a walk, and therefore, you learn to sleep with one eye and one ear half open....Maybe it was helpful because I would have been aware of the fact that, if it happened, he [care recipient] wasn't the only one who ever did it. But I think I lost alot of sleep over it...

The women made few specific comments regarding whether the facilitators of the support groups that they attended were lay or professional. One woman commented that the support group she attended was originally led by a professional. The main purpose for forming the support group was to provide information regarding "elder care" within a given period of time, after which the group would

stop meeting. However, this particular group of caregivers decided to continue to facilitate the group on their own, and to consult experts as the need arose. This woman planned to continue attending, even though her family member had died:

> R:...right now I feel I still can benefit....that's why I went last night. I didn't know how I would feel when I left there but I felt like I'd still like to see them again.
>
> I: The kind of support that they offer you--how would you describe it?
>
> R: Well if you talk about it; if I describe how I [tried] to accomplish something and was unsuccessful, and if I see the humor in it, they see the humor in it too. It's strictly totally completely a non-judgemental sort of sharing.

One woman who was unable to attend support group meetings due to caregiving committments described how reading books about others' experiences provided her with support:

> ...most of the books that I [read]...even if I just sort of snort and say 'that sure sounds like me' when I read it...there's a certain amount of comfort in seeing something in print that is exactly what you're experiencing or [have] felt, but you didn't really want to say it to anybody and you really didn't want to say it to yourself...

Interestingly, as some of the women moved through their caregiving experience, they stated that they would be well qualified to provide advice to future caregivers, by virtue of having been through the experience of working through the

system. One of the main points these women made was that they could help other caregivers to obtain the help that they needed in a much more timely and less stressful and frustrating manner. Thus, informational support from people with actual caregiving experience was valued by the women.

The actions of checking and seeking information were typical of the women as they began their caregiving vigil; however, it is important to note that these activities did not stop as the process of caregiving went on. Many of the women continued their "checking" and their search for information through seeking future medical and/or interdisciplinary assessments, attending seminars, going to the library, reading books, and attending support groups. The women frequently described the need to make choices and decisions throughout the process of caregiving, and therefore information was needed as a basis for caregiving decisions that arose at different times during the process of caregiving.

### Preservative Caregiving

As the women continued their caregiving vigil, they sought to protect and maintain the personhood, health and capabilities of the care recipient by engaging in preservative caregiving. Central to preservative caregiving was the womens' desire to maintain the "former self" of the family member; they wanted to prevent or to slow any deterioration. Preservative caregiving strategies to maintain the care recipient's "former self" were the main focus of the women as they kept their vigil. Their comments provide insight regarding the high priority placed on these activities. Preservative caregiving occurred throughout the overall process of being a caregiver,

and took place in whatever setting the care recipient lived - at home, in a lodge, or in a nursing home. Most caregivers perceived that the care recipient was at risk for loss of a sense of "former self"; loss of present abilities, loss of opportunities to take part in activities that the care recipient previously enjoyed, and loss of dignity and self-esteem. In order to understand the meanings the women attached to their interactions with formal providers as they cared for their family member and sought formal sources of help, it is helpful to examine the range of preservative caregiving strategies in which they engaged.

Preservative Caregiving: Personal Care of the Care Recipient

Strategies to engage in preservative caregiving were employed directly in their care of the care recipient and indirectly in their efforts to access support from formal providers. Strategies employed directly in giving care to the care recipient facilitate understanding of preservative caregiving and the strategies they used with formal providers. These strategies are discussed first.

Several caregivers described strategies that they used to maintain the physical capabilities of the care recipient. Some of the caregivers described how they encouraged the care recipient to continue doing as much as possible for themselves. One woman stated: "...I'm not feeding her 'cause I think that's good that she should, you know, do that herself." Some of the women's strategies involved providing opportunities for the care recipient to walk: "When I'm over there, if I see her sitting in a wheelchair, I'm still fighting to keep her back....So if we go down to the cafeteria, unless she's really too weak, it's with the walker..." This woman also tried

to help her mother to maintain use of her hands and fingers:

> I still like to try and get her to sign cards to my nieces...you can't expect a person at that age to once a month pick up a pen and write [care recipient's name], you know...it's not fair....I usually try and get her to just practice writing 'Love' and 'Mum'...or 'Grandma'...but it's so hard...her hands are gonna stiffen up if all she does with them is feed herself three times a day.

The caregivers also engaged in a variety of strategies to meet the psychosocial needs of the care recipient. Many of these strategies seemed to be based on the caregiver's intimate knowledge of the care recipient prior to the occurrence of cognitive impairment. Strategies used by the women to meet the psychosocial needs of their family member included visiting them as much as possible, maintaining contact between the care recipient and other family members, taking the care recipient on outings, and preparing special foods that they knew the care recipient enjoyed. Some caregivers described personalizing the room of the care recipient in lodge and nursing home settings. Several of the caregivers made a point of conversing with the care recipient regularly: "I try to get up [to the nursing home more often] because she doesn't get enough conversation...and I think the less conversation, the quicker the mind goes." Some of the caregivers tried to keep the family member up to date on family happenings:

> I still talk to her all the time...I can't understand anything she's saying now because she talks so quiet...I talk to her about...her nieces and her grandchildren....and I work at her and try to get a response at some point.

Another caregiver described how she tried to keep the care recipient oriented to the date and time: "I try to determine if he knows what day it is and if he doesn't I tell him and I repeat myself and tell him the day, the date, the hour..."

Attending to clothing and grooming needs was also important to many of the caregivers. Activities included buying clothing in styles and colors that the caregiver knew the care recipient would like, and arranging regular visits to the barber or hairdresser:

> ...she has her hair done every week down at the beauty parlor...it's more for an outing, because...they can shampoo it with the bath....if it wouldn't be too hard...on her scalp, I think I'd have her go twice a week because it's a little pleasure.

The women also attended to the emotional needs of their family member. They believed that it was important to demonstrate to the care recipient that they loved them, that they were an important part of the family, and that they were there for them if they needed someone to advocate for them:

> ...he knows that if something goes wrong and he tells me, I'll try to correct it for him....Out of that, he gets some strength and support that somebody's gonna go to bat for him and that's what he looks for, you know. I guess we all need that.

Some felt that it was important to keep in touch with the care recipient so they would not feel abandoned. Other women described teasing and joking with the family member to keep their spirits up: "...I kind of kid him...and we have some good

laughs....I can usually joke him out of his doldrums, you know...". Several of the caregivers described strategies aimed at maintaining the dignity of the care recipient:

> ...you try and save them from any embarrassment; keep them out of situations where they might say something....even though they don't know that they're being embarrassed - but you know on the good days how they would feel...

Several of the women also described taking the family member on outings, such as going out for a meal or for a drive.

The women watched for signs that the care recipient was more comfortable and happy as a result of their preservative caregiving strategies. Even when the feedback from the family member was minimal or absent, the women continued their strategies to preserve the personhood of the family member, as they believed that their actions made a difference to the family member's health. Changes to the women's preservative caregiving strategies resulted as the family member's health deteriorated and their ability to take part in many of the preservative actions decreased; sometimes the preservative caregiving strategies intensified. For some of the caregivers, physical and emotional fatigue which developed over time resulted in the women decreasing the amount of time spent with the family member doing preservative caregiving.

Preservative Caregiving to Access Support from Formal Providers

As the women continued their vigil as preservative caregivers they maintained surveillance of their family member and were watchful of the care provided to their family member by others. Caregivers noted any signs that indicated a change in the

health of the care recipient, and thus a change in support needs. They continually responded to signs of change in their care recipient's needs or health (and in their own health and capabilities) by gathering more information, examining alternatives and making decisions regarding future care. Interactions between the women and formal health care providers continued to occur as they sought various types of formal support.

The term "formal provider" refers to individual or organizational health care providers, or the health care system. Most of the women commented that they would not hesitate to seek help that would benefit the care recipient in some way. Indeed, they were tenacious in seeking the types of support that they believed would preserve the capabilities or safety of the family member, or that would enable the caregiver to know "what was going on", and thus make appropriate care decisions.

As the women described their continued interactions with formal providers, they shared their insights regarding characteristics that either facilitated or impeded their attempts to obtain the needed support. Their perceptions led the women to use a variety of strategies to either capitalize on the facilitating factors, or, more frequently, to cope with the non-facilitating factors. The characteristics of formal providers described by the women occurred in both institutional and community settings. A description of the strategies used to obtain the needed support, and the womens' perceptions of formal providers follows.

Collaborating. The women who expressed the greatest satisfaction with their interactions with formal providers tended to describe their relationship as

collaborative. They felt that they were part of a team that shared a common goal and provided the care recipient with the best possible care. The two women who described collaborative relationships were pleased with the communication they had with formal providers, which involved sharing of information and inclusion of the caregiver in care decisions. They also tended to express greater satisfaction overall with care provided to the family member.

One woman described how she worked with nursing home staff to solve problems related to changes in the care recipient's health:

> ...we get our heads together with [the] charge nurse,..anytime we have a problem, we all get our heads together and we deal with it.

Another woman described how she collaborated with staff in the nursing home about medicating the care recipient when he became agitated:

> I: ...you mentioned that...when [care recipient] gets agitated, they know whether they need to give medication or not.
>
> C: Right on. I see an improvement in that area for sure. See before, they just wouldn't do anything. It was to the point where he was really belligerant before anything was done, which seems unfair....it's been agreed between us now...that if he...starts to go on the war path...they should administer a small amount [of medication]...

This woman described an event that occurred soon after her family member was placed in a nursing home, and helped to create a collaborative relationship with staff:

> I think one of the things that I really found helpful was...a caregiver's

> conference at [nursing home] after my [family member] had been in there the first year. They had the dietitian...nursing, the charge nurse...the doctor, the physiotherapist...everybody that had a hand in looking after him....I think I learned more from that and felt more at home, more able to relate to those people; better understood what they did and why they did it....I think they should have more [conferences] for [everyone who] has people in those institutions.

Later, this woman described the advice she would give to other family caregivers:

> ...certainly I'd recommend you take time to make an appointment to see [nursing home staff] when they aren't busy....they're never not busy, but they will take time to help you and counsel you...they'll go to the chart...and they'll say...here's why it is, here's what we're doing, here's what [the care recipient is] taking...here's why he's not doing this and here's why we're giving him ground up food. Here's why he's wearing diapers. It's a great resource, it's something that should be utilized for sure ...they're well trained in what they're doing and we're all just learning.

Another woman described how she eventually developed a collaborative realtionship with nursing home staff:

> ...I think it's alot of communication...at first we felt a little uneasy; [we] thought 'maybe we're too demanding and ask too many questions'; but when you...work with them and show them that all you're trying to do is get the best for everybody...then it works okay.

An important characteristic of the collaborative relationship between a caregiver and a formal provider was the ability of the formal provider to provide affirmation to the caregiver. The definition of affirmation developed from this analysis includes the formal provider's recognition of the caregiver's efforts, encouraging the caregiver in her role, acknowledging her special knowledge of the care recipient, and including her in identifying needs and planning care. One woman explained:

> ...it is [easier] for the people at the [nursing home] if they've got someone that they know...really cares about that individual and they can discuss a case with someone...just as we can go to that nurse and talk to her about that patient. I think we feel more free once we found out that you people are more receptive to us, that we're really not just somebody that pays the bills for some other person at the end of the month and that's all there is to it. I think it really has made a difference...

This woman described how her physician provided her with affirmation of her preservative caregiving activities, using humor:

> ...he really liked my mother; he always called me the dragon lady in a term of endearment. He said...'you look after your mother, but you don't let her sit around and vegetate'....he knew how I always kept her going...there were always some little chores for her to do...

In contrast, this woman decribed the lack of affirmational support received from her husband's physician:

> ...last time I took him [to the doctor], he said 'Don't bring him back; there's nothing I can do for him now.' Now my husband doesn't even want [me to] take him back to the doctor...he said 'He doesn't want to see me.' Now, support...is when the doctor says, 'Okay, I cannot help you, but please come back if you don't feel right; just come in and I will see if I can do something for you.'

Another woman commented:

> ...the medical profession cannot even hack long term illness, never mind anybody else. Even Home Care are very tired of looking after [care recipient]. They're very tired of hearing from me....and I will be very very happy to see the last of all the people.

Emotional support from formal providers also contributed to a collaborative relationship. The definition of emotional support that evolved from the analysis is expressions of concern and interest in the caregiver and care recipient; friendliness, a positive attitude, and compassion. This woman described the emotional support she received from formal providers as she cared for her husband at home:

> ...[home care nurse] and [physician] [are] very good. When I see them, they always ask or inquire...people don't realize how much that helps...just asking 'Is there anything I can [do]?'; 'How are things going?'...then you know they care...they wouldn't ask, otherwise.

Another woman described the emotional support she received from staff in the nursing home wher her husband resided:

> ...some of the staff members really seem interested in me as well as being interested in caring for [care recipient] which I think is a really great thing. I think it's nice that they don't shun me and push me aside or say 'oh not you again, you come too often'...they don't seem to mind whatever hours I come. And some of them quite often ask 'How are you today?', or 'What are you doing today?', or 'You look nice today'...

This woman described the emotional support she would like to receive from Home Care:

> ...well that would be nice if the social worker would come out...or phone at least once a month and say 'How are you getting along? How is your husband doing? Do you need anything?' You know, just a phone call...or maybe a visit. She comes out once a year and then she just repeats the forms; that's [the only reason] she comes.

Although the women viewed affirmational and emotional support from formal providers as essential components in achieving a collaborative relationship, they thought that only formal providers who "understood" the caregiver and the cognitively impaired care recipient could provide these types of support. Central to a formal provider's ability to "understand" was knowledge that was based not only on formal education, but also on actual experience with the unique and complex care needs of an older adult with cognitive impairment. Indeed, the womens' perceptions did not appear to be related to the level of educational preparation of individual formal providers. Many of the women for whom emotional and affirmational support were

absent attributed it to a lack of experience in caring for an older person who is cognitively impaired. The women who identified "experience" as an important aspect of "understanding" also stated that only other caregivers would have that experience. A few of the women encountered individual formal health providers who also had caregiving experiences and shared them with the caregiver.

Most of the womens' comments regarding the importance of knowledge and experience arose in their descriptions of situations where they felt there was a lack of knowledge and understanding on the part of formal providers. For example, one woman who lacked affirmational support felt that formal providers tend to "side-step" the caregiver:

> ...if I were to be involved with a family or someone who was having the same problems I have...I could probably tell them the mistakes that I think are made....I would know basically where to start helping them, and largely your help has to be with the main person who is responsible...that's probably what they overlook. Too much side-stepping along the way...when you get into a situation like mine...then one person has to be the coordinator....I think one of the main things is knowing which person that is and not side-stepping them...

Others commented that formal providers' lack of knowledge and understanding led to situations in which the care needs of the care recipient were not adequately met. One woman observed that on the unit for cognitively impaired people where her mother resided, there was never any music playing for the residents to listen to:

> ...overall, there has to be something more, because I see these people who just

> sit and sit and sit and sit, no matter what time you go up during the day. There's no music...[just] silence and just people shuffling around...I really feel that music...sparks something in their memory....I think that's an overall effect that it has on people. I think there have been studies done on that.

This woman also felt that her mother's needs for social stimulation were overlooked because of her mother's cognitive impairment:

> ...over at the nursing home...they don't send my mom on outings anymore because the volunteers do not understand that kind of patient. So my mom doesn't get group outings anymore...if I don't take her on the outings, she won't go.

Another example of how limited knowledge contributed to women's perceptions of inadequate care is in the use of medications. Some of the women felt that formal providers tended to use medication to deal with problem behaviors rather than assessing the behavior and using alternate strategies. The women felt that there was a lack of attention given to the potential negative impact of a given medication on the older person. One woman commented:

> Our only complaint sometimes is that there's [an]...indiscriminate use of drugs...not questioning: 'do you not see that maybe there's something that isn't right here?'...That's what was happening before and nobody questioned it.

Some women also were concerned that there was a tendency among formal providers to over-medicate older adults. One woman linked the problem of over-

medication to the problem of understaffed nursing homes:

> ...that's all we can do now is [to] make it more bearable for him, as long as he's with it, and try to be...an ombudsman against him being over-medicated again...they really are quite happy to have these folks...like zombies...just sitting there out of it, or wandering up and down, kind of thing. It's not their fault...they're understaffed and underfunded, and you do what you have to do.

Another woman described her frustration and anger when she learned incidentally that her mother had been given an antianxiety agent over a long period without her knowledge:

> Everytime [my son and I] would go over [to the nursing home] she was like a zombie....it was bothering me terribly, until I decided that if it's the Alzheimer's, that's fine, but what if it isn't...I called the doctor....He promised to go and see her. I called a week later and he hadn't come. The nurse that answered the phone said 'Oh [caregiver's name], I was just going to call him because I think that your mother should be cut back on the tranquilizers', and I said 'The what?', and I found out at this time that they had her on...Ativan three times a day...this is what her problem [was]....neither one of us [thought]...that she was being doped so badly....then I was really angry, I just thought how cruel, how cruel to my mother, how cruel to me...[I] said 'what is going on, you have no business putting her on this, even through the doctor, without telling me to begin with'....when I felt I was able to cope with it, I arranged a meeting and....they said yes, they were

> at fault, and...I said to them 'What about the person [who] doesn't have someone to look after them or fight for them?...the damage has been done to my mother, but I'm worried about the next person now'....basically, the staff is really nice...and they're really good to mother; she's clean and her nails are cut and things like that...but somebody goofed. How, I don't know because there [are] so many people in an institution...that are looking after these people - that they wouldn't somehow question 'why is [care recipient] like that all the time?' I really question that...

Another woman expressed concern with the limited experience and education of workers coming into her home, through the home care program, to care for her husband who had complex physical and psychosocial needs:

> ...you have people coming into your home...people who have been brought in off the street; limited education, limited background, you don't know who they are, what they are; they're new...they have never had any field work before...and they're being put in with a palliative care case....there is no fine-combing of the attendants.

Many of the women perceived that the lack of knowledge and experience of formal providers contributed to a different, less positive philosophy that indicated formal providers did not share their philosophy of preservative care. This was particularly evident in institutional settings, but was also apparent in the home. One woman's comments indicated that she felt that the goals for care held by the caregiver and by the institution need to be more closely aligned:

> I mean, it's an institution....I'm sure that most of them are the same...but there has to be something in the middle there between the institution and it's care core and the family and it's care core; it's got to be something that...just adds that little bit extra...

Several of the women thought formal providers' philosophy was altered by ageism, or by stereotypes regarding older people. One woman stated that ageism is likely more common among younger formal providers. The women felt that such stereotyping impacted care provided by encouraging use of a "standard" approach in the care of all older people; rather than treating them as individuals. One woman explained:

> ...they're just admitting another person; it's just another patient to them and they've got a pre-set, pre-determined course of events that they're going to take.

Another woman stated:

> ...they're inclined maybe to stereotype people....Especially a younger person; I mean a hundred [year old person] - you're supposed to be out for the count...[but] we knew different.

Some women also felt that stereotyping caused formal providers to treat illness in older adults less seriously. One woman shared the following experience when her mother became ill with a urinary tract infection:

> ...I would go up [to visit]...and it was just awful; she was...weak and uninterested in anything....It was really scary how weak she was

and...listless...they were saying they were feeding her....it just dawned on me that somebody should be checking something...I realized that this was sort of how she began...when she had this urine type of infection...six to eight months earlier....I phoned the nursing supervisor at the nursing home the next day...and said 'I think we should do the basic [urine] test anyway'. I'm not a nurse at all, but I know that's always the thing that is performed. So they got right on it...within a day they had given her the preliminary test and reported to the doctor and they had her on some [medication]....it was just amazing to see how she perked up....Of course I told [my sister] the story and how mad I was...you know...that fall they lost three patients in that unit....when I saw how Mom was let go...granted, they're used to seeing weak people, but it's their responsibility to notice change as well....mother would have been close to...death...if this [had not] been done....nobody saw it...she was just weaker and weaker, and they were accommodating her weakness by keeping her in bed and feeding her and doing nothing about it. So from then on I'm even more into what goes on...that really shook me that she could get that weak...and nobody do anything about it.

When a collaborative relationship was achieved with formal providers, women expressed the greatest satisfaction. Such relationships were characterized by expressions of affirmation and emotional support by the formal providers, and inclusion of the caregiver in decisions related to care of the family member. The presence of ageism or stereotyping by formal providers presented barriers to

collaboration.

Getting along. "Getting along" involved several strategies caregivers used in institutional and home settings to maintain a satisfactory working relationship with formal providers. Many of the women commented that it was difficult for them to get to know the staff as individuals, and for the staff to get to know them and the care recipient. Consequently, the women were reluctant to approach formal providers about issues that were of concern to them. Lack of familiarity with the formal providers also contributed to their uncertainty about who to speak to about a given concern.

Some women felt intimidated by formal providers, particularly in the institutional setting. They were aware of how "busy" and "tired" the staff members were; and described their reluctance to be a "pest". One woman stated that it was not easy to talk to formal providers "...standing there in a uniform...in a hurry and [with] things on their minds". Some caregivers felt that formal providers responded abruptly to their requests for information. Sometimes the women described the perception that staff members seemed to feel threatened by their questions; they thought formal providers viewed the caregiver as "snooping", or 'checking up" on them. The age range of the formal providers also tended to be younger than that of the caregivers, which also posed a barrier for some of the women who wished to discuss their concerns. Several women commented that frequent staff turnover in both institutional and home care settings resulted in situations where formal providers were unknown to them. These barriers led the women to feel that staff were less available to them as a

source of support.

The women who described strategies to "get along" with formal providers believed that this was an important part of their caregiving role. For example, they made a concerted effort to get to know the formal providers. Many women felt that having a good relationship with the formal providers positively impacted the care received by the family member. They felt that "a kind word" for a formal provider may be reciprocated through greater interest in the care recipient and caregiver. This woman expressed satisfaction with her relationship with the staff in the nursing home:

> ...that nursing team down there [at the nursing home]...are a good support team for me....They're strong on my side. I can always talk to [nursing supervisor] or any of those girls that work there; those RN's are just excellent....if I'm going to be away, I explain to them, and they say 'No problem', you know...

Caregivers described a variety of strategies that they used to "get along" with the formal providers. Such strategies occurred both in the home and institutional settings. One woman stated: "...I [find] myself speaking to the girls [at nursing home] more and more in the evening [when] I go down. When I'm there, I try to make a point of talking to whoever is on." Another woman explained that such actions were a part of her support for her mother, who resided in a nursing home:

> ...it's not always the visiting....It's the mending and keeping correspondence up, talking to the doctors, watching everything and talking to the nurses in a constructive way. All those little things are support, not necessarily the

visiting.

This caregiver also stated that if she did find something wrong with the care recipient, "...I get things going....I don't go [to the nursing home]...half cocked either because I'm annoyed...[I say] 'Let's just see what the problem is'..."

One woman described how she became more comfortable with the staff in the nursing home when a period of staff turnover ended:

> ...I'm getting happier with those girls down there all the time. Maybe it's just because I'm getting more used to them or they're getting a little more used to me. Because you know, I like to go and ask questions....I just can't leave him there day in and day out and not care what's [happening], so I question them...'What's he been doing today?'....I want to know what's going on and I like to know what they're going to give him - if they're going to give him drugs....before, it was a new girl every night and I didn't know who I was talking to and she had no idea who I was and what business I might have asking questions.

The women's strategies to "get along" with formal providers were usually described in positive terms. The women also tended to describe feelings of greater satisfaction when they felt they knew the formal providers well enough to speak to them about their concerns and requests for help. However, it was also evident that such efforts were not always stress-free. One woman who cared for her husband at home explained:

> ....a lot of your time is spent just acting as a little go-between [with] all these

> [formal providers] and hoping everybody will get along with everybody, and you are trying to get along with them yourself....My main objective right now is just to keep going....I've moved from dealing with the situation to hoping I can just keep things going at home and keep myself going....It's to buoy everybody up...to keep going for [care recipient] and be cheerful and keep Home Care going and always negotiating, always having to, you know, play the end against the middle and hope [that] somebody won't get angry or quit or [that] this won't fall apart. You're just living like that all the time and that's very tiring.

Another woman, who expressed overall satisfaction with her interactions with formal providers throughout the interviews, stated in her final interview:

> ...we [caregivers] don't always tell [formal providers] everything we'd like to tell them. They're just not another shoulder to cry on...they're paid to do their job....lots of times we're afraid to tell them some of the things we'd like to...

Establishing and maintaining a good working relationship with formal providers was important to the caregivers. For some caregivers, getting along with formal providers was a challenge. Their ability to achieve a satisfactory relationship influenced sharing of information.

Twigging. When the women observed inadequacies in preservative care, or a change in the health status of the family member through their own observations and "checking", they shared this information with the formal providers. The women referred to sharing of information as "twigging" the formal providers to the needs of

the care recipient. For some this was a natural and expected part of their role. This was especially true of the women who felt strongly that families know the care recipient best. However, other women expressed disappointment and concern that they had to bring changes in the care recipient's health status to the attention of the formal providers.

One woman described how she tried to obtain support from nursing home staff regarding putting in her mother's dentures and hearing aid every day. She believed that such needs were "basics", and important for the care recipient's quality of life. She described her frustration when arriving to visit her mother and finding, on several occasions, that these basics had been neglected.

> ...I notice where I would like them to do more, like just be more careful. I mean, I've hung up a thing right by mom's sink saying how to put a hearing aid battery in 'cause they'll...put it in backwards. I mean there's no way - if you turn it on it's either dead or it's in backwards....as I say, you can only nag so often...whenever I go up there I make sure that they know if they've put it in wrong...whether it follows on or does anything, I don't know....Yeah, really it's a lack of thoughtful concern. Like they're there, they're nice and everything, but it's the little things, like if she doesn't have her teeth in. I mean, how can you let an older person eat when...you know, they must know that there's teeth....oh, I
>
> was quite annoyed when I went up there and there she is eating and none [no teeth]....it's the basic things that are so important up there...that mean a lot to

> older people; they can't hear and they can't chew...you know.

Part of this woman's frustration was related to the fact that the care recipient could not communicate these needs to her formal providers herself:

> ...I wonder, for all the times I go up and these things aren't done, what happens all the times I'm not up? Does she go a whole day with her hearing aid not turned on? It shouldn't be, you know, as far as I'm concerned. It shouldn't be; these are the basic things that...should be of concern.

Another woman was concerned about her mother's declining appetite, and was disappointed that she had to ask nursing home staff to give her Ensure (a dietary supplement). One woman notified nursing home staff when she thought her mother may have a urinary tract infection:

> ...I spoke to the nurse and I said I thought there was this strange smell to her urine, and I said didn't anyone notice that, and I would like them to ask the doctor if it could be a bladder infection....I said maybe she wasn't getting enough fluids...the doctor did check on that and they started giving her more fluids....after they checked that...she seemed to be a lot better....that's something that disappoints me sometimes is that it has to come from me...I have to say...'I think there's something wrong here.'

Safety of the family member was also a concern. One woman discovered by chance that her mother had wandered out of the nursing home in cold weather without the staff's awareness:

> ...I went up to the staff and asked them about it. They told me 'yes'; she had

> gone out without her coat on...I was really upset and I said 'How can that be...you have a desk right at the front door....you know that people in this nursing home are not capable of caring for themselves...somebody should be responsible if they go out the door'....I kicked up a really, really, really big fuss about it....then they got a system [so] that when the door would open, it buzzed..."

Another woman felt that her husband was getting left out of socialization activities at the nursing home: "...I've had to have a meeting there and ...speak up lately because he just sort of gets left out, unless you keep an eye on things."

Twigging the formal providers into their concerns was not necessarily stress-free. It seemed that the women who found that they were on the formal providers' "case" frequently feared retaliation against the care recipient. One woman explained:

> ...it kind of concerned me that anytime I made a big fuss about something or other that they would retaliate on my Mom....that was a big concern to me that they would be rough with her or something like that....when her glasses disappeared at one time, I [wondered] 'did they take them away from her?'...because I had complained about something...

Twigging also included caregiver strategies to teach others, including formal providers, about how to be helpful. One woman found that she had to teach the care attendants who came into her home how to meet the complex care needs of her husband:

> ...I train almost every attendant that comes; you have to be prepared to

> invest a lot of your free time at first, and hope and pray that...this person will be satisfactory and will remain with you at least a few months, so you get a pay off for your time...

Another woman who cared for her husband at home commented:

> ...it's so hard to have somebody come and take over with a person who isn't capable of talking properly and who can't carry on a conversation...you have to try and tell that [person] what to do and what to say, and it's just...so much easier to do it yourself and make it as simple as possible.

Some of the women also commented that understaffing and staff turnover resulted in poor communication between formal providers involved in the care of the care recipient. They noted that staff who were unfamiliar with the care recipient were less likely to detect subtle changes in health status. This sometimes resulted in the perception that the care received by the family member was inadequate or inconsistent. One woman explained:

> ...even a change in staff, like [staff] that don't know their patients - well okay, 'where is all her padding [on her bedside rails] so she doesn't get these bruises?' - it's not there again. All of these little things that [are] very important to us, but maybe a busy person that [does not] know the patient or [is not] watching the chart wouldn't notice. They're all frustrations to the family because you know that it avoids a problem that you know is going to come up.

The women employed a variety of mechanisms to "twig" formal providers to

the needs of the care recipient, and to teach formal providers how to provide care. Although some considered this an expected part of caregiving, others were disappointed that it was necessary.

Fighting/struggling. Several of the woman also described their interactions with formal providers using terms such as fighting and struggling. There were consistent themes in the stories of these women. First, the women tended to make statements which indicated that they would do whatever they had to do in order to obtain the help needed. Second, their descriptions of attempts to obtain support were characterized by waiting long periods before obtaining the help needed, rejection of initial requests for help, appealing decisions regarding the amount of support they should receive, and persevering in their search for help. Such experiences were highly stressful for the women. Conditions that seemed to result in the women feeling that they had to fight for help included a lack of affirmation of the caregiver in her role, bureaucracy, and a lack of understanding of the needs of care recipients and their caregivers. The strategy of struggling occurred both in institutional and home settings.

One woman described how she planned to persevere in order to obtain information regarding the medications that her mother, who resided in a nursing home, was given. This woman previously received an itemized list of her mother's medications and dosages every month. When the mother was reassessed at auxiliary level care, the woman no longer received that information because the government paid for the medications:

I'm not getting an itemized list from them....they will give the normal print

> out of the drugs the doctor orders....But not the specific amount in a month that is actually administered to her, which is what I want....I will not let it rest. There will be some way....maybe I will have to go as far as being declared a legal guardian...which I will do.

Another woman described her frustration when she had to wait for necessary equipment for her home before her husband could be discharged home from the hospital:

> ...it went back and forth...I had to change the whole back entry...because he couldn't [do] stairs...we put a lift in...they told me there is a grant for people like that. So I applied for the grant and I was pushed on time because [the hospital] had to discharge him....and Home Care put some bars up and they [installed] a raised toilet seat...they did as much, I guess, [as] I pushed them for or asked them for. And I was on the phone everyday....I said 'I need this. and I need this.' So I was between the [name of hospital] who would like to send him home and Home Care who had the red tape from here to Rome; it was just ridiculous. Everytime I asked for something, 'Well, we have to have a meeting. We have to discuss it.' And it was just a drag...and it made me so angry....for my husband's foot care, I fought for six months in order that somebody comes out every six weeks to do his feet....In my eyes it shouldn't be.

Another woman described her battle to obtain sufficient personal care support for her family member, whom she cared for at home:

> I had many encounters with Home Care over the years, and as his condition got worse, I have battled it out with Home Care...I have worked very hard on that....I do qualify for the time and I did get it...[but] with the Home Care situation, you have to remember that it is re-evaluated very frequently and at any moment, you may be cut back or you might have to go to bat for what you've got in the first place.

This woman went further to describe the advice she would give to other caregivers:

> ...you have to be prepared for a long, long wait with the services...applications for pensions, you're looking at a year to a year and a half....it goes on forever; you just have to keep on going....[caregivers] have nothing to lose, so they might just as well plug along and do it....if you want something, just don't back off; I mean if you keep at it long enough...they're gonna say yes to get rid of you.

Fighting/struggling occurred in both community and institutional settings. This strategy reflected both the caregiver's perseverance and the stressful conditions that led to this approach.

## Conclusion

Analysis of the caregiver and focus group interview data has revealed that women caregivers of older family members who are cognitively impaired keep a vigil by monitoring the health of the family member and by searching for information that will assist them in their caregiving. Further, the women are preservative caregivers who place a high priority on maintaining the health and capabilities of their family

member whenever possible. The women caregivers' perceptions of themselves in the caregiver role and of the needs of the cognitively impaired family member facilitate understanding of how the women interact with formal providers. Facilitating and non-facilitating factors encountered in their interactions with formal providers led the women to utilize a range of strategies to obtain the needed support: collaborating, getting along, twigging and fighting/struggling. Information, affirmation and emotional support were the three types of support that were most important to the women caregivers.

# Chapter 5

## Discussion

Keeping the vigil and the actions of providing preservative care for a cognitively impaired family member are consistent with aspects of other caregivers' experiences reported in the literature. The discussion will first address factors influencing the womens' role as caregivers. The second part of the discussion will address the themes of keeping the vigil and preservative caregiving in relation to other qualitative research of informal caregivers. The discussion concludes with exploration of relevant theoretical perspectives on formal support.

### Influencing Factors

The womens' philosophy of life and keen sense of filial responsibility toward family members (Brody, 1981), the presence of a strong marital commitment (Wright, 1993), and the influence that such factors exert on women as they take on their caregiving role is well documented in the literature. The women's special knowledge of the family member was an important aspect of what they believed they could contribute to preservative care and they placed a high priority on sharing information as the care recipient was cognitively impaired, and unable to communicate with staff on their own behalf. Others (Bernardini et al, 1993; Tobin, 1989) have also recognized dementia as a barrier to accurate assessment of care recipients, which then compromises the ability of formal providers to give care, particularly in an institutional setting. Bernardini et al (1993) described staff failure to recognize adverse clinical events as a consequence not only of the inability of the care recipient

to communicate, but also of the stereotype held by formal providers that care of the chronically ill means custodial care.

An unexpected finding was that several womens' perceptions of what formal providers and others in the community expected them to contribute influenced their role as caregiver. The women in this study described a keen awareness that they were in a publicly funded system which provided an important reason for the judicious use of health care funds. Chappell (1992) points out that the current generation of seniors reached adulthood before the advent of a publicly-funded health care system in Canada, which may provide another explanation for the apparent influence of expectations of formal providers on their role, and their desire to utilize formal help only as a "last resort". It is important to acknowledge that this finding may differ from studies conducted in the United States because of the inherent differences between the health care systems in the two countries.

## Themes of Keeping the Vigil and Preservative Caregiving in Relation to Other Qualitative Studies

The central caregiving actions described in this study resembled the actions of caregivers identified in other qualitative studies. These studies focused on the philosophy of caregiving held by family caregivers as they provided care for a cognitively impaired family member, their caregiving actions, and their perceptions of the support received from formal providers.

The literature reports findings similar to this study concerning family caregivers' search for information, which was an important part of keeping the vigil.

Examples in this study included seeking a diagnosis or information about the health care system and available resources, including support groups. The caregivers' search for information about "what is happening" in the present study is consistent with Lindgren's (1993) description of the first stage of the "caregiver career" - the Encounter stage. The women in both studies wanted information about the illness process, behavioral symptoms, and the caregiving skills they would need. Chenoweth and Spencer (1986) also described experiences of caregivers that were similar to those of the women in the present study. For instance, in their study caregivers tended at first to mistrust their own perceptions of the changes that were occurring in the family member; they also had difficulty articulating these changes to the physician. Some also reported difficulty convincing the physician that something was wrong. The resistive nature of the cognitively impaired family member added to these difficulties, and resulted in delays in obtaining a diagnosis. These findings are similar to the current study. When physicians provided a diagnosis of dementia, the majority focused on the hopeless nature of dementia, they did not engage caregivers in discussions of dementia or offer suggestions for coping with problem behaviors and accessing resources; some caregivers were advised not to bring the family member back, as "nothing could be done". As in the current study, the few caregivers in Chenoweth and Spencer's study who did feel supported were those who reported that the physician held a conference with the family for a thorough discussion of the illness, and offered to be available to the family for future questions and concerns.

Filinson (1985) found that there is a tendency for physicians to present the

diagnosis and prognosis to families in vague and obscure terminology, with the result that the disease is dealt with privately as a personal problem, rather than as a public health issue. Wilson (1989) also identified similar issues in her description of the caregiving process of "searching for explanations". The result was that caregivers had few alternatives but to "take on" the caregiving role without fully understanding the implications. There is also the risk that families who do not receive adequate explanations may respond inappropriately to the needs of the care recipient.

Filinson (1985) stated that a diagnosis of Alzheimer's disease tends to bring people together in organizations under a single "label", and reduces the isolation of family caregivers, even though their individual experiences may be diverse. The comments of the women in the present study were simialar. Willoughby and Keating (1991) also reported in a qualitative study that a diagnosis of Alzheimer's disease provided a "label" and access to the Alzheimer's Society, which provided information through written material and support groups.

There has been extensive research regarding the use of support groups for obtaining the information needed for caregiving. Similar to the experiences of some of the women in the present study, Gonyea (1989, 1991) reported barriers to regular attendance at a support group, including transportation, inconvenient time or location of the meeting, and lack of someone to care for the family member in the caregiver's absence. Crossman, London and Barry (1981) identified factors that may make support groups more accessible and effective for family caregivers, such as referrals, individual contact with group members, announcements and newsletters; this was also

reflected in the women's comments in the present study. It is also recognized that caregivers attend support groups for a variety of reasons such as acquiring information, problem solving, and sharing experiences. New caregivers who attend support groups early in their caregiving may find information from "veteran" caregivers disturbing (Lindgren, 1993); this was experienced by one of the caregivers in the present study. This raises the question of whether the benefit of obtaining information from either support groups or individual counselling may vary at different times or phases of the process of caregiving.

Bower's grounded theory study of intergenerational caregivers yielded findings that are congruent with characteristics of both keeping the vigil and preservative caregiving as found in the current study. Bowers (1987) identified five categories of caregiving that were defined by *purpose* rather than by associated tasks. *Supervisory caregiving* is consistent with the overt checking strategies that were part of keeping the vigil for women in the present study. *Preventive caregiving* involved prevention of illness, injury, and physical and mental deterioration, as well as active monitoring by the caregiver. *Protective caregiving* (protecting the care recipients' self-image and awareness of dependency) was viewed as the most important and also the most difficult type of caregiving to provide. This is consistent with the preservative caregiving described in the present study which included protecting the esteem and dignity of the care recipients, and providing care in a way that the care recipient was unaware of being cared for. *Instrumental caregiving* involved the "hands-on" caregiving activities that maintained the care recipient's physical health status, and

was described by the caregivers as the least important type of caregiving. The preservative caregivers in the present study, however, viewed cleanliness and grooming as important basic needs. Unlike Bower's findings, the caregivers in the present study did not identify one aspect of care as more important than the others, nor did they view the different types of care as conflicting with each other. Chesla, Martinson and Muwaswes (1994) in a qualitative study described a similar desire of family caregivers to maintain the dignity, safety and functional abilities of the care recipient through careful monitoring and provision of good care.

Bowers (1988) also explored caregivers' perceptions of care provided by nursing home staff in another qualitative study of caregivers of older family members whose cognitive status ranged from non-confused to severe mental impairment. The caregivers in Bower's study believed that quality care included knowledge and expertise in both *technical* and *preservative* care, and that technical care provided in the absence of preservative care would result in the care recipient's loss of dignity, hope and sense of control over the environment. Depression of the care recipient was the ultimate affective outcome which the families interpreted as evidence of poor care.

The definition of preservative care in the present study differs somewhat from Bower's definition; the women in this study viewed their care as not only preserving the dignity and hope of the family member, but also as contributing to their mental and physical status. Another difference is that the indirect (covert) observations made by the caregivers in the present study included talking to family members of other residents in the nursing home to obtain information about care provided in their

absence, but were not reported by Bowers. The strategies caregivers use to monitor the care activities of nursing home staff in the current study were however similar to those reported in another qualitative study by Duncan and Morgan (1994), including: watching to determine if the care recipient was treated as a person rather than an object, watching the care recipient's reaction to staff, and watching how staff treated other residents of the nursing home. Hasselkus' (1988) qualitative findings also described the tendency of caregivers to critique and supervise the care provided by professionals.

Like the caregivers in the current study, caregivers in Bower's (1988) study perceived a lack of skilled care providers in the nursing home setting. They noted several problems as evidence of poor quality care: failure to recognize a change in the care recipient's condition (e.g., due to a disease process or problem with medications); failure to communicate important information about the care of the care recipient to other staff leading to inconsistent care; stereotyping, and rigid policies and scheduling. Although a few women in the present study commented on how much they appreciated staff who updated them on the care recipient's status, several described issues such as under staffing, under funding, and staff turnover, which they felt was a reflection of the fact that most care in nursing homes was provided by staff with minimal or no training. Bowers (1988) drew distinctions between care provided at home and care provided in a nursing home, stating that nursing home placement marked the beginning of 'sharing the caregiving' with other non-family members. In the present study, however, women who cared for their family member at home also

shared caregiving tasks with formal providers from Home Care, and expressed a similar awareness of how family and formal providers define quality care differently.

The women in the present study sought affirmational and emotional support from formal providers. In a qualitative analysis of focus group and one-on-one interview data, Duncan and Morgan (1994) found that family caregivers of cognitively impaired elders placed the greatest emphasis on the *relationship* of staff members with the care recipient and the family caregiver as an indicator of the provision of quality care, and placed little emphasis on the technical tasks performed by staff. More specifically, caregivers viewed respectfulness and a caring attitude of the staff toward the caregiver and care recipient as essential components of quality care. In their relationship with nursing home staff, the caregivers in the current study wanted to share their knowledge of the care recipient prior to the occurrence of cognitive impairment, and their caregiving experience with the family member prior to institutionalization. Bowers (1988) similarly stated that quality preservative care requires *biographical expertise*; that is, knowledge of the past life of the care recipient, which indicates the uniqueness of the individual care recipient's needs. In Duncan and Morgan's (1994) study, the caregiver's relationship with staff was enhanced when staff recognized the special knowledge of the caregiver; this enabled the caregiver to feel part of a team with a shared commitment.

Several barriers to collaborative relationships with staff were expressed by the caregivers in the present study. Others (Duncan & Morgan, 1994) also found that an ongoing relationship with the staff was essential in order to influence their behavior

through the caregiver's use of role modelling and providing positive feedback to staff. Barriers to the establishment of an ongoing relationship with staff included organizational issues that are frequently generic to institutional settings, such as an emphasis on the performance of technical tasks, as well as staff turnover.

Similarities with other research were also noted regarding the caregivers' perceived need to tell formal providers how to care for the care recipient, and to remind them when something was not done (Hasselkus 1988). The strategy of "twigging", used by the women in the present study, is consistent with the subtle and direct methods described in Bower's (1988) study. The barriers to educating staff were also similar: feeling intimidated by staff, fear of angering staff, and caregiver uncertainty of who to talk to. Duncan and Morgan's (1994) description of caregivers' efforts to build relationships with staff and to share their knowledge and observations with them is also consistent with the "getting along" and "twigging" strategies of the women in the present study. There was, however, no reference in the current literature to the "fighting" strategy used by the caregivers in the present study.

In one study (Hasselkus, 1992), staff in an adult day care employed strategies similar to those of the family caregivers in the present study. The study used ethnographic interviews and participant observation to explore the meanings for caregivers of the daily routines and activities engaged in by staff at a day care center for persons with Alzheimer's disease. The staff 's guiding principles for the day program were *preventing harm*, *keeping it calm*, *catching trouble early*, and *providing some meaningful purpose*. Hasselkus commented: "I felt the strain of this constant

vigilance..." (p 201). The staff at the program focused on activities that were *preventive* and *enabling* for the participants, as opposed to *restorative*. The activities were provided in a safe and predictable environment. Hasselkus postulated that such activities were more appropriate than restorative goals, considering the fluctuating capabilities of the person with Alzheimer's disease. The women caregivers in the present study reported a similar emphasis on preventing and enabling by supporting the functional capabilities of the care recipient, and providing opportunities for social interaction. It is important to note that the family caregivers of the people attending the day program expressed satisfaction with the program, feeling that the family member was safe and well cared for.

In an earlier ethnographic study of caregivers of the frail elderly, Hasselkus (1988) identified five themes of meaning in family caregiving, only one of which, caregivers actions, is visible to others. Health professionals and family caregivers each have their own *invisible meanings* they attach to the caregiving situation. Bowers (1987) also concluded that caregiving involves both observable behaviors and mental activities.

Bowers (1987) points out that the invisibility of the *process* of caregiving makes it particularly vulnerable to influence by outsiders, such as formal providers, who are unaware of what the caregiver is trying to achieve, or who may consider other types of care more important. Hasselkus (1988, 1989) noted that tension in the caregiver/formal provider relationship is created when caregivers and health professionals hold different, and often incompatible meanings of the caregiving

situation, which they do not make known to each other. Tension also occurs when family caregivers perceive that their goals for care, and their views on how to attain the goals, are not consistent with those of formal providers. Hasselkus (1989) concluded that there is a need to "...reconceptualize the professional-caregiver relationship....as a partnership involving the exchange of expertise, values, and interests" (p 654-655).

Because formal providers and family caregivers each possess an expertise that must be shared with each other in order for quality care to occur, Bowers (1988) contends that a collaborative approach to caregiving is more appropriate than a division of tasks, and argues that a division of tasks will only perpetuate formal providers' inattention to preservative care, and foster conflict between formal and informal caregivers. Perhaps the tendency of formal providers to use a standard approach to caregiving interferes with their ability to consider the *situation-specific* view of caregiving held by individual caregivers described by Hasselkus (1989).

Collaboration is less likely to occur when there is a lack of understanding of the other's perspective of the situation. In the present study, the women who received affirmation and an opportunity to share their special knowledge with formal providers tended to describe their relationship as collaborative, and to express satisfaction with the care provided. Other women described barriers to a mutual sharing of meanings. Duncan and Morgan (1994) concluded:

> "...when we say 'sharing the caring', what families seek to share is not so much the *tasks* involved in caring for the resident as it is the *process* of caring about the resident" (p 244).

## Summary

The women caregivers' actions to keep their vigil, including information-seeking activities and strategies to monitor both the care recipient's health status and the care provided by others are similar to those reported in the research of others. Preservative caregiving, which includes actions to preserve the dignity and capabilities of the care recipient, and strategies to share information and build collaborative relationships with formal providers also resemble those reported in other studies of family caregiving. Similarities were also noted regarding factors that either facilitated (affirmation of the caregiver's special knowledge) or posed barriers (stereotyping, staffing issues) to establishing a collaborative relationship with formal providers. A unique finding of this study was the strategy of "fighting" used by some women to obtain formal help. It is also important to note that the vigil as preservative caregivers described in this study occurred in both home and institutional settings.

## Theoretical Perspectives

The key findings of this study bring us back to the fundamental question of how informal and formal care providers work together. Considerable interest has been generated over the past two decades regarding the relationship between formal and informal systems of care, resulting in the development of models that explicate their respective roles. In this part of the discussion, the models that have been put forward to date will be described, and empirical evidence that support them will be presented. The main aspects of each model will also be discussed in relation to the findings of the current study.

Hierarchical Compensatory Model

Cantor's (1979) model of the relationship between informal and formal sources of support postulates that there is a hierarchical order of preference in an older adult's choice of source of support that is dictated by the primacy of the relationship of the caregiver to the care recipient. The older person tends to view the family (spouse and children) as the most appropriate source of help. When family is absent, friends, and then neighbors are called upon to act in a compensatory manner. Cantor identified factors that may impact an elder's choice of support, but clearly stated that only when help is unavailable from the informal sources, or the nature of the help required extends beyond the resources of informal helpers, does an older person turn to the formal system for assistance. Subsequent research indicates lack of empirical evidence for such a relationship between the informal and formal systems of care, suggesting that the use of one system of care does not predict greater or lesser use of the other system (Chappell, 1992; Penning & Chappell, 1990). Support for the model is however found in studies that report the prevalence of (as opposed to preference for) informal support provided, and use of the formal system as a last resort for help (Chappell, 1992; Penning, 1990).

The findings of the present study are consistent with the hierarchical compensatory model in that the daughters and daughters-in-law were called upon for assistance only when the wives of the care recipients were unavailable to take on the role of primary caregiver. The women in the present study also indicated their preference for informal rather than formal sources of support, and their intention to

use formal support as a last resort.

Substitution Hypothesis

Similar to Cantor's (1979) model, this hypothesis also postulates the primacy of family members when an older person requires help. Shanas (1979) found that non-institutionalized community elderly preferred support from spouses and children when they were ill, and that extended family members linked the older person to bureaucratic institutions and the community when needed. Both the hierarchical compensatory and substitution hypotheses postulate that one source of help may substitute for another, but with a preferred ordering; formal help is used as a last resort when informal resources are depleted. The substitution model also suggests that as formal support is provided, there is a similar decrease in the amount of informal support provided. As indicated previously, there is little support in the literature for the substitution hypothesis (Chappell, 1992; Penning & Chappell, 1990).

The actions of the women caregivers in the present study to maintain involvement in the care of their family member in the presence of formal care provision contradict the suggestion of this model that informal support decreases as formal support increases. However, congruency was noted in the many instances in which the women sought to connect their cognitively impaired elder to appropriate sources of formal support.

Task Specificity Model

In contrast to the hierarchical compensatory model or the substitution hypothesis, Litwak (1985) argued that it is the structure of the task involved which is

more important in determining who will provide the needed support. The main tenant of this model is that formal and informal group structures are different, with each group excelling at different functions. Litwak states that informal groups, which are motivated by affection and duty are better at performing non-uniform, unpredictable and diffuse tasks that do not require technical knowledge. Formal organizations can provide services that require technical knowledge and large-scale human resources (Litwak, Jessop & Moulton, 1994). A further premise of this model is that dividing the labor between informal and formal groups promotes greater efficiency in task performance and prevents conflict resulting from structural differences in the groups (Noelker & Bass, 1994).

Limitations of the model are that it does not address specific desired outcomes for care recipients and their informal and formal caregivers; nor does it account for the variance that exists among informal and formal systems (Noelker & Bass, 1994). There is some empirical evidence in support of this model (Litwak, 1985; Penning, 1990). However, further testing is required that uses a wider range of tasks for which older adults receive assistance, and relies less extensively on hypothetical situations (Noelker & Bass, 1994). Chappell and Blandford (1991) reported that there is seldom a complete division of labor between the two systems of care, nor do they tend to specialize in areas of assistance provided. As Hasselkus (1988) pointed out, "...tasks in and of themselves may not be the most important part of the caregiving experience nor the most appropriate focus for facilitating formal and informal cooperation" (p. 686). Litwak, Jessop and Moulton (1994) have extended work on the task specific

model to examine how life-course variables influence the use of formal sources of support at different stages of the life course. Further investigations that address a variety of conditions and stages of life is called for at this time.

The strategies of the women in the present study to collaborate with and to "twig" formal providers regarding the care needs of their family member conflict with the main contention of this model that the structure of the task should determine the appropriate source of support. Indeed, some of the caregivers in this study were involved in teaching technical aspects of care to the formal providers, as well as bringing changes in the care recipient's health to their attention. Further, the performance of diffuse and unpredictable caregiving tasks frequently led to caregiver exhaustion and subsequent requests for formal help.

Supplementary Model of Care

The supplementary model of care hypothesizes that formal care supplements the care provided by informal sources, particularly when the needs of the older family member exceed the resources and capabilities of the informal helpers. This model differs from the task-specific model because formal and informal providers assist with the same tasks. In a study that examined the impact that provision of formal care services for homebound elderly had on informal care by family and friends, Edelman and Hughes (1990) concluded that formal care supplemented the care provided by informal caregivers, particularly when there was a decline in the health of the care recipient, and their care needs increased. Further, they contended that informal caregiving remained stable over time.

The findings of the current study are consistent with the hypothesis that formal care supplements informal care when the care needs of the family member exceed the available informal resources. The womens' continued involvement in caregiving in the presence of formal help provision also supports the contention that informal support remains relatively stable over time.

Complementary Model of Care

This model proposes a complementary relationship between the formal and informal systems of care that is characterized by a sharing of tasks rather than a division of tasks which is postulated in the task-specific model. In a study that explored the characteristics of those who do and do not make use of both formal and informal systems of care, Chappell and Blandford (1991) concluded that the two systems are complementary either when the informal system is less available to older individuals, or when the informal system is unable to provide all of the needed care. This model contains elements of both the supplementation and compensatory models. In a survey of seniors with functional disabilities, Denton (1997) reported support for the complementary model of care, with more emphasis on the compensatory rather than the supplemental effect of formal assistance. The desire of the women in the present study to share the tasks and decision making involved in caring for a cognitively impaired elder is consistent with the complementary model of care.

## Summary and Conclusion

Although the above models suggest possible linkages regarding the relationship between formal and informal systems of care, research to this point is inconclusive on

the nature of the theoretical relationship. In contrast to the emphasis that the models place on determining who provides what type of care and when, the findings of the present study suggest that family caregivers tend to place greater emphasis on their interactions with formal providers as a means to secure the care needed by their family member.

At this time, theories related to the linkages between the informal and formal systems of care do not address the process or the nature of interactions that occur between informal family caregivers and formal health care providers. The strategies of collaboration, getting along, twigging and fighting used by the caregivers in the present study suggest that the relationship between family caregivers and formal providers is not a passive one; rather, it is a relationship characterized by the caregiver's continual monitoring of care provided, sharing information and negotiation regarding goals for care.

Current literature in the area of caregiving and support is only beginning to acknowledge that informal caregivers wish to maintain responsibility for the care of their family member, even in the presence of formal care provision. The desire of the women in the present study to maintain a vigil and to provide preservative care indicates that caregivers want to remain involved, and that they do not perceive their role as diminishing over time. Greater insight regarding caregivers' perceptions of their role may contribute to improved conceptualizations of the linkages between formal and informal systems of care.

## Implications for Practice

In the presence of health care reform and an aging Canadian population, there is a great deal of interest in linkages between formal and informal systems of care with respect to policy formation. At this time, the issues of cost and of family responsibility figure prominently in the ongoing dialogue (Chappell, 1992). As policy makers have become aware of the cost savings resulting from informal care, there is a concern that increased provision of formal services to seniors is too expensive, and will lead families to "shirk" their responsibilities. However, studies that have examined these issues indicate that such concerns are unwarranted, as the amount of informal care does not decrease with the provision of formal assistance. Such a stance also ignores the indirect social costs of caregiving, such as decreased labor-force participation and erosion of the caregiver's physical and emotional health (Noelker & Bass, 1994).

In view of increasing pressures on women to assume caregiving responsibilities and the high priority caregivers place on collaboration with formal providers, it is important that health care providers promote greater involvement by family caregivers. Adoption of primary health care principles of public participation and accessibility of health care services (Stewart, 1995) could provide a basis for system reform. These principles have potential to provide a basis for forging effective relationships between formal and informal caregivers of cognitively impaired older adults.

The strategies employed by the women caregivers in this study to keep their

vigil and to provide preservative care raise implications for formal providers as they interact with family caregivers. Improved understanding of the meanings of the caregiving experience held by family caregivers will enhance the ability of formal providers to establish and maintain collaborative relationships in care provision.

Contact and collaboration with formal providers is particularly important at the beginning of the caregiving experience to assist the caregiver to acquire the knowledge needed in order to provide appropriate care (Chenoweth & Spencer, 1986). Providers need to be alert to the potential importance of inconclusive symptoms and high levels of family stress that may interfere with the caregiver's ability to absorb information initially. It is also important that formal providers include other family members in addition to the primary caregiver in information-providing sessions, as one of the difficulties that caregivers report is a lack of understanding and support by other family members.

Although caregivers in the present study as well as in other studies emphasize care that benefits the care recipient, it is well acknowledged that the well being of family caregivers is also at risk. The decision to institutionalize a cognitively impaired relative is not only related to the behaviors of the cognitively impaired elder, but also to caregivers' illness or exhaustion. Caregivers require support and counselling in the early phases of caregiving to reinforce the importance of maintaining and protecting their own health.

## Implications for Research

Several implications arise from the findings of this study for research. As the

populations ages, more people will develop cognitive impairment, and more family members will be involved in their care. Formal health care providers who work with cognitively impaired older adults and their family caregivers require additional knowledge generated through research in order to facilitate optimal care of this vulnerable population.

More needs to be understood about the relationships between formal and informal caregivers throughout the process of caring for a cognitively impaired elder. Research is needed that addresses the perceptions of both formal and informal care providers of cognitively impaired older adults; findings may help to facilitate a mutual sharing of meanings and collaboration between the two systems of care.

The barriers encountered by caregivers as they attempt to access formal sources of support also warrant further study. Identification of mechanisms for sharing information regarding diagnosis and community resources in an appropriate and timely manner is also a potentially fruitful area of future research.

Finally, future research needs to continue to utilize theory-generating methodologies that will continue to uncover dimensions of the caregiving experience which have not yet been brought to light, and also provide greater depth and understanding of those already identified.

## Study Limitations

A frequently identified limitation to secondary analysis is the fact that the secondary analyst was absent when the original research question was asked and when the data were collected. This may contribute to decreased insight on the part of the

secondary analyst into hidden factors that may have influenced the data collection (Jacobsen, Hamilton & Galloway, 1993), and the potential for misinterpretation of the data by the secondary analyst. Secondary analysis also precluded the use of theoretical sampling in the collection of data to directly address emerging research questions pertaining to formal support. These limitations were balanced by the involvement of the principal investigator of the original study as thesis supervisor in the present study, by the use of contextual information to enhance interpretation, and by additional data collection in two focus group sessions.

Sample bias is another potential limitation. The sample is self-selected by virtue of volunteering to participate in the study, and therefore cannot be viewed as representative of all women caregivers of cognitively impaired older adults.

## Conclusion

This study has identified that women caregivers' perceptions of formal support and their interactions with formal providers are influenced by their perceptions of themselves and the care recipient. The caregivers' primary focus was maintaining a vigil over their family member. This core focus was supported by their preservative caregiving. Tension occured in relating to formal providers when the women perceived that formal providers' goals for care of the care recipient differed from their own, and when barriers interfered with their ability to collaborate. In addition to collaborating the women described getting along, twigging and fighting/struggling as they related to formal providers in their focus on preservative caregiving. The perceptions of formal support reported by the women caregivers in this study may

provide direction to formal providers regarding future interventions with family caregivers.

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# APPENDIX A

## Guiding Questions for Interviews

### Initial Interview

In this study we are interested in learning about your relationships with family and friends while you are looking after _____. In particular, we want to understand the process of give and take in your relationships.

Support Within Social Network

1. During the past few weeks what are some examples of specific situations in which you experienced help (support)? Please describe who was involved and what they did to assist you.

2. From which relationship(s) do you receive most of your support or help? How would you describe these relationships (e.g., length of involvement, type of support, frequency of contact, difficulties)?

3. During the past few weeks while you have been caring for (dependent adult/infant)*, what are some examples of specific situations in which you have given help to other people besides (dependent adult/infant)?

4. How would you describe those relationships within which you provide most of the help in terms of length of involvement, type of support, frequency of contact, difficulties (other than relationship with dependent)?

5. Are you sometimes hesitant to accept or ask for help? If yes, please describe the situation.
Are you sometimes hesitant to offer help? If yes, please describe the situation.

Caregiving Relationship

1. What is a typical day like for you in caring for _____?

2. In describing your relationship with (dependent adult/infant), what do you contribute to the relationship?
What does _____ contribute?

3. Does what you think is important in life affect your relationship with _____?
In what ways?
Does what you think is important in life affect the way you think about caring for _____?

4. Sometimes people find it difficult to care for someone who can contribute only a little to a relationship. Does this apply in your situation? If so, how?

Demographic Data

In order to describe the women who have participated in the study, we would like you to answer the following questions:

1. What was your age on your last birthday? (Years) _____

2. Indicate by an X the amount of formal education you have:

Less than Grade 12 _____

Grade 12 _____

Some university or post high school diploma _____

University degree _____

Graduate degree _____

3. Into which category would you place your yearly family income?

Less than $20,000 _____

$20,000 to $40,000 _____

over $40,000 _____

4. What is your current or past occupation?

5. For mothers of preterm infants: (N/A)*

6. If you are caring for an older person who is confused:

a) Please mark with an X each of the major difficulties which the person you care for experiences.

unaware of the time _____
unaware of where they are _____
unaware of who is around them _____
forgets events in the recent past _____
forgets events in their early life _____

b) Do you live with the older person you are caring for? _____

## Follow-up Interview(s)

### Changes in Social Network

#### Help provided to others.

1. Have there been any changes in how you are able to help others since (your baby was born/when you first started caring for _____)? Could you please describe the changes?

2. Which if any of these changes have occurred since our last interview?

3. Do you expect any changes in the future? In what ways?

#### Help received from others.

1. Have there been any changes in how others have helped you since (your baby was born/you first started caring for _____)? Could you please describe the changes?

2. Which if any of these changes have occurred since our last interview?

3. Do you expect any changes in the way others help you in the future? In what ways?

### Changes in Caregiving Relationship

1. Have there been any changes in your relationship with (your baby/with _____) since you first started caring for him/her? Could you please describe the changes?

2. Which of these changes if any have occurred since our last interview?

3. Do you expect any changes in this relationship in the future? In what ways?

## Final Interview Guide

This is the last time I will be talking with you. I would like to review some of the things that you discussed with me previously (insert individualized questions).

### Changes in Relationships

1. Are there any changes that have taken place in your relationships since our previous interviews? Please describe any changes in your relationships with others. Please describe any changes in your relationship with (your baby/with _____).

### Social Network

1. In our previous conversations I have asked you to select and describe situations in which you received or provided help. Today I will ask you for similar information using specific examples of situations other researchers have used. These questions may give us the same information as before or provide additional information. (The Barrera ASSIS will be used).

### Debriefing

As we conclude our discussions about your relationships with your family and friends while you are looking after _____, I would be interested in hearing your thoughts about the experience of participating in this study. In what ways, if any, has your involvement in the study influenced your thinking about your relationships and the process of give and take in your relationships?

*Interview guide was used in a collaborative project involving mothers of preterm infants.

# APPENDIX B

## Guiding Questions used in Focus Group Interviews

### Introduction

In our discussion, issues that have emerged from the analysis will be described, and you will have an opportunity to share your comments about each. Your experience may be different; if it is, we would like to hear about it. You may also discover that your experience is similar to others. In the discussion, it is important for us to hear as many different points of view as possible.

### Questions

1. Re: Strategies to protect the personhood of the care recipient

   (Examples provided, using short quotes from interview data)

   a) In what ways (if any) did this perspective influence your interactions with formal providers?

   b) How important was this issue for you when gaining formal help with protective caregiving?

   c) Were your experiences with decision-making similar or different?

2. Re: Strategies to obtain formal support

   (Examples provided, using short quotes from interview data)

   a) In what ways is this similar to or different from the methods you used to obtain formal support? Were there other methods that you used?

   b) Are the checking strategies similar to or different from you own experience?

   c) Some things seemed to make it easier to obtain formal help. (Examples provided, using short quotes from interview data) Are these things similar to or different from your own experience?

   d) Some things seemed to make it more difficult to obtain formal help. (Examples provided, using short quotes from interview data) Are these things similar to or different from your own experience?

# APPENDIX C

## Consent Form Used in Original Study

Faculty of Nursing
University of Alberta

Research Study: Women as Caregivers: Perceptions of Reciprocity in Social Networks

Researchers:
Principal Investigator
Dr. Anne Neufeld
Associate Professor
Phone: 432-6764

Co-investigator
Dr. M. Margaret Harrison
Associate Professor
Phone: 432-5931

The purpose of this study is to understand the social relationships of women who are caregivers. This study will provide no direct benefits to you but the results of the study will help nurses plan programs to assist other women who are caregivers.

You will be interviewed 3 - 5 times during a 12 month period; each interview will last 1 to 1 1/2 hours. The interviews will be held in your home at a time you choose and will be tape recorded. You will be asked to describe your relationship with the adult or baby* you care for and to describe the help that you get from and give to others. You will also be asked to say what you consider to be important in life.

The information you give in the interview will be typed out. Your name will not appear on the typed interviews, the questionnaires, or in any reports of the study. During the study, only code numbers will be used to identify the interviews and questionnaires which will be kept in a locked file cabinet.

At the end of the study, the code list will be destroyed. The information you have given will be stored in a locked file cabinet for possible future analysis by either Dr. Neufeld or Dr. Harrison. Before the information is looked at again, the researchers will get permission from the appropriate ethical review committee.

Taking part in this study is voluntary. You may refuse to answer any question and may withdraw from the study at any time by telling the interviewer.

If you have any questions while you are participating in the study, you can contact either Dr. Neufeld or Dr. Harrison. A copy of this consent will be given to you.

_____ _____

Research Assistant Signature of Subject

_____

Date

*This consent was used in a collaborative project involving mothers of preterm infants.

# APPENDIX D

## Consent to Participate in Focus Group Discussion

**Project Title: Women Caregivers of Older Adults with Cognitive Impairment: Perceptions of Formal Support**

**Researcher:**
Myrna Heinrich, RN
MN Candidate
Faculty of Nursing
University of Alberta
Phone:

**Thesis Supervisor:**
Dr. Anne Neufeld,
Professor
Faculty of Nursing
University of Alberta
Phone:

**Purpose:** This study will add to our understanding of the support women caregivers receive from nurses and other health workers.

**Procedure:** A group of women who were in a previous study will take part in a group discussion. The title of the study was: *Women as Caregivers: Perceptions of Reciprocity in Social Networks*. The discussion will take place at a time and location that is agreeable to the women. After the women are introduced to each other, they will receive a report about support from health workers. The report will include quotes from the study, without the use of names. The women will comment on how their experiences were either similar or different. Dr. Neufeld will be present. the meeting will last about 1 1/2 hours. It will be tape recorded, then typed out by a typist.

**Participation:** There will be no harm to you, nor will you benefit directly from being in this study. The results from the study may help nurses and other health workers to care for other caregivers in the future. You do not have to be in this study if you do not wish to be. You may refuse to answer any question. You may withdraw from the study at any time by telling the researcher.

Your name will not appear on the typed copy of the discussion or in any reports about the study. The consent forms will be stored in a locked cabinet, separate from the information that you give during the meeting. The tape will be stored in a locked cabinet with the typed copy from the meeting. The typed copy and the tape will be kept for possible use in another study in the future. Before the information is used again, the researcher will get approval from the ethical review committee.

The findings of this study may be published or presented at conferences. Your name or any material that may identify you will not appear in the report. If quotes from the discussion are included in the report, a make-believe name will be used. Any material that may identify you will be changed. If you ever have questions about this study, you can call the researcher or her supervisor at the phone numbers above.

**Consent:** I give my consent to take part in this study. I have a copy of this form to keep.

_____ _____
(Signature of Participant) (Date)

_____ _____
(Signature of Researcher) (Date)